Does HIV matter when you are poor and how?

The impact of HIV/AIDS on the psychological adjustment of South African mothers in the era of HAART

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Abbreviations

AIDS	Acquired immunodeficiency syndrome
ANOVA	Analysis of variance
ARK	Absolute Return for Kids
ART	Antiretroviral therapy
ARV	Antiretrovirals
ASSA	Actuarial Society of South Africa
BSI	Brief Symptom Inventory
CES-D	Centre for Epidemiologic Studies Depression Scale
CHC	Community health centre
CIDI	Composite International Diagnostic Interview
CIS	Clinical Interview Schedule
CNS	Central nervous system
CSSR	Centre for Social Science Research
DALY	Disability adjusted life years
FHH	Female headed households
HAART	Highly active antiretroviral therapy
HADS	Hospital Anxiety and Depression Scale
HIV	Human immunodeficiency virus
ICRW	International Centre for Research on Women
IVDU	Intravenous drug users
MOS-SSS	Medical Outcome Study Social Support Survey
MSM	Men who have sex with men
NGO	Non-governmental organisation
NSP	New strategic plan
OSSREA	Organisation for Social Science Research in Eastern and Southern Africa
PGWC	Provincial Government of the Western Cape
PHC	Primary health clinic
PLWHA	People living with HIV and AIDS
PTSD	Posttraumatic stress disorder
SANAC	South African National AIDS Council
SCID	Structured Clinical Interview for the DSM
SCL	Symptom checklist
STD	Sexually transmitted disease
STI	Sexually transmitted infection
SWAA	The Society for Women and AIDS in Africa
TB	Tuberculosis
UCT	University of Cape Town
UK	United Kingdom
UNIFEM	United Nations Development Fund for Women
US	United States
WHO	World Health Organization
YLD	Years lived with disability

Abstract

Does HIV matter when you are poor and how? The impact of HIV/AIDS on the psychological adjustment of South African mothers in the era of HAART

The study investigated the psychological adjustment of HIV-infected South African mothers living in poverty in the era of HAART. One hundred and eighty adult women living in long-term poverty who were the primary caregiver of at least one child under 18 years were administered a structured questionnaire. The sample comprised infected women (n=130), some but not all of whom were on antiretroviral therapy, as well as a comparison group of non-infected women from the same community (n=50). Of those who were receiving antiretroviral therapy (n=80), half had just commenced treatment and half had been on treatment for six months. In addition, five women were selected as case studies and followed up with in-depth interviews for six months. Data were analysed using analysis of variance, planned comparisons and multiple regression, and narrative analysis respectively.

Results showed that HIV status had a significant, independent impact on levels of depressive symptoms but not anxiety. HIV positive women exhibited significantly more symptoms of depression and anxiety than seronegative women, regardless of their stage of disease. An irregular household income, poorer perceived physical health and the use of avoidant coping predicted higher levels of depressive symptoms amongst infected women, while less active coping and greater avoidant coping predicted higher levels of anxiety. Avoidant coping was the best predictor of levels of depression and anxiety amongst women, independent of HIV status. When assessed at six months after commencing treatment, antiretroviral therapy had had no impact on anxiety. However, levels of depression were lower than amongst women who had just commenced treatment.

Qualitative data of women's own accounts supported the role of HIV in psychological distress, but pointed to poverty as an underlying narrative through which women's experiences of living with HIV were continually filtered. While HIV was sometimes the source of disruption and disturbance, it typically lacked salience in the presence of HAART and for women who were relatively asymptomatic, particularly given the substantive poverty-related stressors that women faced on an ongoing basis.

Key findings indicated that HIV status contributed to the mental health burden experienced by women living in poverty, and that longer-term use of antiretroviral therapy was associated with reduced depression. Since avoidant coping was the best predictor of poor psychological adjustment, it may be an appropriate focus for future targeted mental health interventions for this population group. However, the fact that poverty had considerable, and even greater, salience for women at times, should also inform the planning and provision of services.

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It's all too much: too much sickness, too much sadness, too much death. Women are the resilient force that sustains the [African] continent, and they are being eviscerated by a virus.

Stephen Lewis, United Nations' Special Envoy for HIV/AIDS in Africa
(Lewis, 2004)

...despite the existence of some excellent laws and sound policies, many communities are failing to protect women and girls from infection and from the social consequences of AIDS. ... although women's resilience and strength are well known in Africa, the 'coping skills' they possess are not an infinite resource.

Kofi Annan, United Nations' Secretary-General
(UNAIDS, 2004c, p. 3)

When I heard that I've got it [HIV], I did not worry myself at all. I just told myself that everybody has got it; the person who does not have it is the one who has not tested. Even here [the clinic] you see that it's full; everyone has got this. Even older people, they can be your mother's age, but they have it. ... HIV has never been a problem to me. My major problem has always been finances. There were times when I couldn't even afford bath soap; I didn't even have clothes to wear.

Zoleka[1] (interview 3)

[1] A pseudonym has been used.

Preface

This dissertation emerged out of an interest in women's issues and a concern for socially minded research with genuine applicability in the South African context. Next to India, South Africa has the largest number of people living with HIV/AIDS (UNAIDS, 2006), with black African women representing the largest single group of infected individuals amongst these. There is compelling evidence that the burden of care for both children and adults on these women is often considerable. Also the poverty in which they live plays an important role in their lives as well as contributing to their risk profile (to be discussed in Chapter 1). One such risk is to women and mother's mental health.

Mindful of this set of issues, and with a belief in the importance of evidence-based policy, this dissertation set out to make a scientifically rigorous, socially relevant contribution to the field of HIV and mental health in South Africa. The details of this undertaking and the thinking behind its design are presented in the chapters that follow.

Briefly, the research aimed to answer the question of whether HIV-infected women and mothers are less well adjusted, psychologically, than women who are not HIV-infected, and then to try and understand the answer to this question further. The most important part of this further enquiry was whether it was actually women's HIV status that explained differences in their psychological adjustment (if any). In addition, were they less well adjusted than if they were simply living in poverty, given that poverty has been linked to poor mental health outcomes? Other issues considered interesting from a research and policy perspective were: whether the roll-out of antiretroviral therapy would impact on women's mental health; and whether other kinds of issues, such as how many children women cared for, the extent of their social support and the types of coping strategies they used, contributed to their emotional wellbeing.

Although a quantitative, population-based approach to this investigation was considered essential, it also required conversations with women regarding their personal experiences

and views of living with HIV or AIDS in a poverty context. It is for this reason that both a quantitative and qualitative component was included in the research.

The dissertation that follows is structured as seven chapters:

To begin with, two literature chapters are presented: Chapter 1 is largely policy oriented and reviews the evidence regarding the mental health of people living with HIV/AIDS (PLWHA), with an emphasis on women living in poverty in developing contexts. Chapter 2 presents a review of the research evidence regarding the psychological and psychosocial adjustment of HIV-infected women and mothers. A methodological critique will be critical to this review. Following from the points raised in both these chapters, the particular contributions of the present study will be discussed along with its aims and objectives.

Chapters 3, 4 and 5 outline the study and its findings in detail. Chapter 3 presents the study design and methods, including the cross-sectional study and the longitudinal, qualitative case studies that were conducted. Following this, Chapters 4 and 5 present the results of each component of the study separately. This will comprise statistical analysis of questionnaire data and narrative analysis of interview data collected for the qualitative study.

The two final chapters situate the present study in the policy context and research literature outlined in Chapters 1 and 2, as well as considering its implications. Chapter 6 provides an integrated synthesis of the findings of both parts of the study, and discusses them in light of prior evidence and the present design more generally. Some of the parameters of the qualitative work and limitations of the quantitative study will also be outlined. Chapter 7 presents concluding remarks and considers the implications of the study's findings. This comprises recommendations for future research and policy and service planning with respect to the mental health of HIV-infected women in South (and southern) Africa.

A note on terminology:

Two terms employed in the title, namely, "mothers" and "psychological adjustment", are central to this dissertation and will be used repeatedly. Regarding the term "mother", its

use in this study will be discussed in more detail in Chapter 3 (section 3.2.3.2), with the main point being that it is used to refer to women who *adopt the role of mother*. The term is therefore used more broadly than simply women who have a biological relationship with the child for whom they provide care. Consequently, the study also concerns "women" since many women are mothers in that sense. This is reflected in the fact that much of the literature on women includes those who adopt a primary childcare role. For these reasons, the literature review includes studies conducted with women and mothers, and the term "women" will be used most often during the dissertation. The relevance of the care role which defines "mothering" will, however, be the subject of later analysis (as a predictor of women's psychological adjustment).

A range of terms with similar meanings to "psychological adjustment" are in use and tend to belong to different disciplines, in addition to having different denotations and connotations. The terms "psychological adjustment", "psychological wellbeing", "distress" and "emotional wellbeing" are most often used within psychology and will be used interchangeably throughout the dissertation. "Psychosocial wellbeing" is a broader term that refers to the relationship between psychological and social experience. This term will mainly be used when referring to studies that employ qualitative methods to describe women's psychological experiences, often in the context of their social setting and its particular challenges (for example, poverty). For the same reason, this term will be used when reporting on women's own accounts of living with HIV and AIDS in the present study. The term "mental health" is the narrowest of the group of terms and is most often used within psychiatry and clinical psychology to refer to levels of distress and dysfunction in individuals that meet the threshold for a clinical (diagnosable) disorder. However, it is also used to refer to less serious levels of distress, and is the preferred term within policy and service discourses. It is for the latter reason that the term "mental health" will also be used frequently in this dissertation.

The use of these various terms at different points in the dissertation also reflects the fact that the work straddles several disciplinary boundaries, as well as using a qualitative approach (narrative) that straddles several other disciplines, too. Most notable amongst these disciplines are clinical psychology, cultural psychology, psychiatry, social work, public health, medical sociology, gender studies and literary studies.

CHAPTER 1. SETTING THE POLICY CONTEXT: WOMEN, HIV/AIDS, POVERTY AND MENTAL HEALTH

The present dissertation is situated at the intersection of four key concepts: HIV/AIDS, women/mothers, mental health and poverty. This chapter discusses each of these concepts and their interrelationships in order to provide a context and rationale for the research. Further, given that the current empirical investigation was conducted in South Africa, the South African epidemic will be positioned in relation to the global epidemic as well as that in sub-Saharan Africa wherever possible.

The purpose of this chapter is not to present an exhaustive review of each of these areas, but rather to sketch a framework for the present study. In so doing, this chapter draws largely on seminal papers and international reports, including the work of the most prominent researchers in the field (for example, José Catalan, Seth Kalichman and Vikram Patel). This will be followed in Chapter 2 by a detailed discussion of the literature more narrowly relevant to the present study, namely the literature on the psychological adjustment of women and mothers infected with HIV/AIDS.

1.1 THE FEMINISATION OF THE EPIDEMIC

Some twenty-five years into the epidemic, several things have become clear, amongst these the fact that HIV/AIDS is increasingly a disease of women living in poverty (Farmer, Connors & Simmons, 1996). While HIV was once viewed as a disease of homosexual men and intravenous drug users, the proportion of infected women has been increasing worldwide, particularly in areas where heterosexual sex is the dominant mode of HIV transmission (UNAIDS, 2004a). Further, it is the economically and socially disadvantaged who are most vulnerable to infection in all communities and countries, including the richest nations (Whiteside, 2002).

According to the latest UNAIDS (2006) figures, globally, 39.5 million people were infected with HIV in 2006, of which 17.7 million were adult women (aged 15-49 years). Women make up 48% of all infected adults, a number which rises to 59% in the epicenter of the pandemic – sub-Saharan Africa. Although it contains only 10% of the world's population, sub-Saharan Africa is home to 63% of PLWHA (UNAIDS, 2005) and eight out of every ten children orphaned by AIDS (UNICEF, 2003). Despite the fact that changes in incidence and rising AIDS mortality has caused global HIV prevalence to level off, the number of people living with the disease continues to rise due to population growth and the life-prolonging effects of antiretrovirals. This is nowhere clearer than amongst poor women.

Seventy-five percent of all HIV-infected women live in sub-Saharan Africa, one of the poorest regions in the world and the only one where women make up more than half of infected adults (the figure for the Caribbean is 50% followed closely by the Middle East and North Africa and Oceania) (UNAIDS, 2006). Between 2004 and 2006, numbers of HIV-infected women rose by 1 million, with the rate of incidence among young women compared with young men particularly telling (ibid). Globally, amongst 15 to 24 year olds, women are 1.5 times more likely than men to be infected (UNAIDS, 2005), while young girls in southern Africa are 2.7 times more likely to test positive (UNAIDS, 2004c). The gendering of the epidemic is even more pronounced in some countries in southern Africa, with girls and young women making up 80% of all infected youth in Zimbabwe and Zambia (ibid). HIV infection rates are also very high amongst pregnant women, reaching one in five or higher in six African countries (Botswana, Lesotho, South Africa, Swaziland and Zimbabwe)[2] and as high as 39% in Swaziland (UNAIDS, 2006). Given the prominence of the epidemic among youth and young adults, and the high rates amongst pregnant women, many infected women are also mothers or primary caregivers of children.

In South Africa, the country with the largest number of PLWHA, comparisons between different subgroups similarly reveal the prominence of the epidemic among poor women specifically as well as women in general. Five percent more women than men are infected with HIV in South Africa (13.3% versus 8.2%) (Shisana et al., 2005) and women have a

[2] Note that only the figure for Botswana is based on a population-based survey. The others all draw on antenatal surveys that are likely to overestimate rates amongst pregnant women in general given the overrepresentation of poor women in these samples.

higher proportion of deaths due to AIDS than men (33.8 versus 29.8%) (Bradshaw et al., 2003). Overall, one in five South African (adult) women is HIV infected (Shisana et al., 2005), while figures based on attendance of antenatal clinics show that more than a quarter of pregnant women in six of the nine provinces are HIV positive (Department of Health, 2006d), with the projected national prevalence rate for 2005 at 25.6%[3] (Actuarial Society of South Africa, 2005). The higher prevalence for African females (24.4%) compared with women in general (20.2%) also reflects the high representation of poor women given that the African population represents the poorest sector of South African society (Shisana et al., 2005).

1.2 GENDER INEQUALITY AND HIV/AIDS

The increasing feminisation of the epidemic raises two particularly interesting and interconnected issues: one relates to the reasons for women's heightened vulnerability to infection and the other to the differential impact of HIV/AIDS on both affected and infected women. It will be shown that an attempt to address both questions leads to the need to acknowledge the profoundly social nature of the disease, and the fact that HIV is both fuelled by and fuels gender inequalities and the feminisation of poverty.

1.2.1 Physiological, social and economic vulnerability to infection

In the first instance, it must be acknowledged that HIV is a disease and that there are physiological reasons why women are more vulnerable to infection than men. Evidence shows that the rate of infection via unprotected sexual intercourse is between 1 and 8% from woman to man, while it is 20% from man to woman (Aberg, 2005). There are several important reasons for this difference (Africa Region Gender Team, 2000; Baingana, Thomas, & Comblain, 2005). First, a substantial proportion of the female genital tract is permeable to fluids, compared with male's anatomy. Second, semen contains a higher concentration of the virus than female secretions. Third, cervical ectopy[4] which facilitates

[3] This figure is for the population ages 15 to 59 years.

[4] This refers to the thinning of tissues on the surface of the cervix, thereby exposing delicate tissue that is more easily disrupted and vulnerable to the transmission of a virus such as HIV (Personal communication, Dr James Bull, 25 July 2006).

HIV infection is common in young women (Baingana et al., 2005). Fourth, pre-existing sexually transmitted diseases (STDs), which increase the likelihood of infection ten fold (ibid), are more likely in women. This is due to the fact that STD symptoms are less apparent in women, thereby delaying detection and diagnosis (Strebel, 1995).

Women's physiological vulnerability is, however, exacerbated by entrenched social and cultural norms regarding masculinity and femininity that render women disempowered and unequal members of their societies. While 'women' cannot and should not be treated as a homogenous group, this is the dominant cultural narrative and one that holds particularly for women living in poverty – those most affected by the epidemic and the focus of this dissertation. As Farmer (1996, pp. 23/4) argues:

> ...women have been rendered vulnerable to AIDS through *social* processes ... economic, political and cultural forces that ... shape the dynamics of HIV transmission.... All sexually active women share to some extent biological risk, but it is clear that the AIDS pandemic among women is strikingly patterned along social, not biological lines.

Prevailing cultural norms, particularly at the epicenter of the pandemic, construct women as subordinate, dependent and passive, dictating silence regarding sexual matters and valuing virginity and chastity amongst women (but not men) (Africa Region Gender Team, 2000; Gupta, Whelan, & Allendorf, 2003; UNAIDS, 2004c). Women are often treated as legal minors, barring them from inheritance and independent financial decision-making (ibid). Further, as will be discussed in more detail later, women are valued for their ability to reproduce and for their role as mothers and carers.

Data from 35 of 48 countries in sub-Saharan Africa show that men are 20% more likely than women to have correct knowledge of HIV (UNAIDS, 2005), while 80% of young women globally have insufficient knowledge to protect themselves against infection (UNAIDS/UNFPA/UNIFEM, 2005). Further, this is more likely among the impoverished than at higher income levels (Gupta et al., 2003). Also consequent on gendered social norms, women often have older male partners who are more likely to have a STD – a risk factor for infection (Baingana et al., 2005).

Gender-based violence also renders women vulnerable for a number of reasons. Fear of violence or abandonment often prevents women from discussing fidelity or negotiating condom use with their partner (Gupta et al., 2003), and makes them more vulnerable to coerced sex, including rape and other sexual practices such as dry sex (Africa Region Gender Team, 2000). A study conducted in South Africa in the early 1990s reported that a large percentage of women believed that men had the right to multiple partners (62%), that they did not have the right to refuse sex with their partners (49%), and that their partner would get angry (51%), leave them (30%) or threaten violence (28%) if they requested condom use (Abdool-Karim, Abdool-Karim & Nkomokazi, 1991 in Outwater, Campbell, & Abrahams, 2005). Research in Africa on the link between intimate partner violence and HIV showed that infected women in Tanzania were two and a half times more likely than seronegatives to experience partner violence (UNAIDS/UNFPA/UNIFEM, 2005), while South African women beaten by their partners were 48% more likely to be infected (Outwater et al., 2005).

Economic vulnerability also contributes significantly to gendered sexual practices that place women at risk of infection. Women have less command than men over assets, including productive resources, employment and education. Moreover, they experience pressure to feed their children and families. This renders them vulnerable to abuse and exploitation, including being more likely to exchange sex for money, and less able to negotiate safe sex or leave a risky or abusive relationship (Africa Region Gender Team, 2000; UNAIDS, 2004c). Further, just as economic inequality drives HIV infection, HIV exacerbates inequality amongst women by forcing them to forego educational and economic opportunities in lieu of caring for the infected and affected (Baingana et al., 2005). As Treichler and Warren (1998, p. 112) suggest, "[o]ne might even say that women contract HIV infection not only because of 'what they do', but because of 'who they are'".

1.2.2 Differential social and economic impact

In addition to driving women's vulnerability to infection, gender inequality is highlighted and exacerbated by the epidemic. Not only are women overrepresented by the numbers for all of the reasons discussed above, it is now widely recognised that the epidemic has a disproportionate social and economic impact on women (UNAIDS, 2004c). Here two main

issues will be discussed: First, poverty is a significant risk factor for HIV and HIV has contributed to the increasing feminisation of poverty; and second, economic inequality and gendered social norms (as already mentioned) contribute to the burden of care experienced by women in the context of HIV/AIDS.

1.2.2.1 Poverty and HIV/AIDS

Farmer and Kim (1996) have noted that poverty, alongside gender inequality, is the reason why the fastest growing epidemics are among women. Independent of gender, there is clear evidence that poverty contributes to the risk for, and transmission of, HIV/AIDS, as well as being an effect of the epidemic. While epidemiologists point to different subtypes of HIV and routes of transmission across the globe (Greenblatt & Hessol, 2000), the clearest pattern is that HIV is most prevalent and has increased most rapidly in the poorest communities. Poverty, and its associated stressors and characteristics, creates the "path of least resistance" in which the infection thrives (Lindegger & Wood, 1995, p. 7).

Whiteside (2002) provides an excellent discussion of this relationship, including some points that have already been raised. Only two important issues will be mentioned here. First, most infections occur via sexual transmission, and the nature of sexual activity is determined by economic (along with social and cultural) factors (Baingana et al., 2005; Whiteside, 2002). The poor, and poor women in particular, are more likely to have multiple partners, to trade sex or engage in transactional sex, and to remain in risky relationships for economic protection, thereby making them vulnerable to HIV infection. Second, communicable diseases such as HIV thrive in poverty (Stillwaggon, 2006; Whiteside, 2002). Stillwaggon (2006) argues that two characteristics of people living in poverty, namely, high rates of malnutrition and parasite infection, render them suitable hosts for the spread of an infectious disease such as HIV. Malnutrition, poor nutrition and parasite infection undermine immune response, increasing susceptibility to HIV transmission and advancing disease progression. Consequently, Africa (along with other poverty-stricken regions) is "fertile terrain" for HIV/AIDS (Stillwaggon, 2002).

However, as Whiteside (2002) notes, there is a cycle between HIV/AIDS and poverty, with AIDS also causing poverty and increasing inequalities at every level, from individual and

household to global. Examining evidence from across the African continent, Whiteside outlines several of these impacts, amongst them the fact that food consumption in affected households has been found to fall by 15-30%; AIDS pushes household incomes down by up to 80% and increases household poverty; it undermines the attainment of gender equality by keeping young girls (rather than boys) out of school to care for sick relatives; and, at a more macro-level, undermines public and government efforts at poverty reduction (Loewenson & Whiteside, 2001 in Whiteside, 2002).

Evidence from available survey research in South Africa substantiates these findings, demonstrating the extent to which HIV and AIDS can be "the tipping point from poverty into destitution" in already poor households by exposing them to further economic shocks and undermining household security (Booysen, 2002; Booysen, 2003; Booysen, 2004; Booysen, Bachmann, Matebesi, & Meyer, 2004; Nattrass, 2004; Steinberg et al., 2002, p. i; Yamano & Jane, 2002 in Booysen, 2004). The fact that those living in poverty might also be more susceptible to HIV infection contributes to the completion of this cycle in a context such as South Africa (Tladi, 2006).

1.2.2.2 HIV/AIDS and the feminisation of poverty

Without engaging in the debates about the technical correctness of the term (BRIDGE, 2001)[5], it is clear that HIV/AIDS has contributed to the feminisation of poverty. By this is meant two things: First, there is a higher incidence of poverty among women than men, and second, there is a trend toward greater poverty among women associated with a rise in the number of female-headed households (FHH; ibid). A third related point is that the poverty experienced by women is more severe than that of men (ibid).

Statistics cited by both the World Health Organization (2000) and the United Nations Development Programme (1995 in Budlender, 2004) indicate that 70% of people living in poverty are women or girls. Moreover, the increase in number of poor rural women in 41 developing countries over a 20-year period was 17% higher than the increase in poor men (World Health Organization, 2000). With respect to female headship, the numbers are

[5] See BRIDGE (2001) for a detailed discussion of the limitations of data used to argue for the feminisation of poverty.

high. On the African continent, one in five households with children in sub-Saharan Africa and one in three in southern Africa are female-headed (Monasch & Boerma, 2004; UNICEF, 2003). The proportion of female-headed households is higher in southern Africa than in any other part of sub-Saharan Africa, and almost double the rate in West and Central Africa (where the prevalence of HIV is also lower) (UNAIDS, 2004c; UNICEF, 2003). Of the southern African countries, the country with the largest epidemic, South Africa, has the third highest number of FHH's at 46% after Botswana at 52% and Namibia at 47% (Monasch et al., 2004; UNICEF, 2003). (In parallel with the spread of the epidemic) there is some evidence of an upward trend in eight of the twelve countries in sub-Saharan Africa in which demographic surveys were available, as well as evidence of a link between poverty and female-headed households (BRIDGE, 2001). Certainly an increase in the number of FHH's in the poorest and most affected region in the world is suggestive in this regard.

It is true that many households in South and southern Africa were female-headed even prior to the epidemic, and tended to experience more economic strain than those headed by men (UNAIDS, 2004c). However, HIV/AIDS has exacerbated this situation, leaving women in impoverished communities already under considerable strain, largely responsible for ensuring the viability of households. Recent survey data in South Africa suggests that only 12.5% of women who are household *heads* have a partner present in the home (Ziehl & Burns, 2004). Further, the differential experience of poverty in these households has been attributed to their lower earning capacity and competing domestic interests and expectations (BRIDGE, 2001). Poverty for women is more than simply income deficiency, it encompasses disadvantage with respect to other forms of impoverishment, including literacy and education, skills, and employment opportunities (World Health Organization, 2000). Many more women than men are employed in the informal sector where incomes tend to be lower or irregular and there is often a lack of protection through labour law (for example, work in unpaid subsistence agriculture, as street traders, or in low-paid domestic work) (Budlender, 2004). For the fourteen countries which fall under UNIFEM's regional office, female income is only a fraction of male income, the lowest being 39% in Swaziland (ibid). South African women earn 45% of the income of their male colleagues. Not only do these factors render women more vulnerable to poverty, it suggests that they have fewer opportunities to escape once poor.

1.2.2.3 The care burden on women in HIV affected households

The second indication of the differential impact of HIV on women is the heightened burden of care they experience as a function of their gendered social and economic status. Reproduction and motherhood is a feminine ideal and a valued role in many cultures, but most especially in the African context (Tabi & Frimpong, 2003; Upton, 2003). Since children are viewed as a symbol of wealth, motherhood elevates women's social status (Were, 2000), affording them a social identity and in many cases guaranteed status in kinship groups (UNAIDS, 1999 in Gupta et al., 2003). However, the construction of women's care role that is most salient in the context of the HIV epidemic is that it is a natural role (see Burman, 1994). Childbearing is seen as a woman's obligation (Were, 2000) and by extension, although largely at an implicit level, so is the care of children.

Globally, women and girls provide up to 90% of informal care due to illness in addition to many other tasks they already perform, including taking care of children and the elderly, cooking, cleaning and other domestic tasks (UNAIDS, 2004c; UNAIDS/UNFPA/UNIFEM, 2005). In the context of HIV/AIDS, both sick men and women tend to be cared for by female relatives, and women are more likely than men to take in orphaned children (Evans, 2005; Monasch et al., 2004; UNAIDS, 2004b; UNICEF, 2003; Upton, 2003). Throughout the sub-region, where mothers die, orphaned children are more likely to reside in female- than male-headed households[6], with a large proportion of these children orphaned by AIDS[7]. Evidence shows that female-headed households have on average two orphans per household, while male-headed households have 1.6 (Monasch et al., 2004). Figures for the residence of double orphans in South Africa indicate a similar pattern (UNICEF, 2003). Further, a South African survey of AIDS-affected households showed that women or girls were the primary caregivers in two out of three households, and the only caregiver in one out of three of these households (Steinberg et al., 2002).

[6] None of the documents that were cited provide a definition of female-headed or male-headed households. However, one UNAIDS document, while citing figures on female-headed households, refers to the "intense pressure to feed and care for their families" that women and girls experience (UNAIDS, 2004c, p. 8). This suggests that a female-headed household is likely one in which women are responsible for sustaining the household financially as well as carrying out care tasks typically considered the domain of women and girls.

[7] Only one study is available that disaggregates data according to the cause of children's orphan status, namely AIDS versus other causes of death, thereby delineating the unique ontribution of the AIDS epidemic to the large number of orphans in sub-Saharan Africa (see Cluver, Gardner, & Operario, in press).

The overrepresentation of women in child- and other care roles within the family or household should, however, not be confused as meaning that only mothers care for children (Bray & Brandt, in press). Responsibility for childcare varies across countries and regions. For example, in sub-Saharan Africa, children, orphans and non-orphans are most likely to live with their parents in Eastern Africa and least likely in southern Africa, with patterns of residence for non-orphans a fairly good indicator of patterns for orphans (Monasch et al., 2004). While 90% of non-orphans in Burundi live with both parents, 25% of children in South Africa, Botswana and Namibia live with neither mother nor father (ibid).

However, the fact that care in the context of HIV/AIDS is referred to as a burden to women, or as having reached crisis proportions (UNAIDS, 2004c), suggests that the construction of women's role as valued is overly simplistic. In fact, the assumption that this valued role is natural enables it simultaneously to be rendered invisible and undervalued. Where time-use surveys have been used to document household and domestic activities, childcare in particular is either not mentioned or listed as a secondary activity (Chobokoane & Budlender, 2001). Further, where childcare involves supervision (i.e. takes place while the carer is involved in another activity at the same time), it is not reported at all (ibid). In her study of child labour in the Zambezi Valley, Reynolds (1991, p. 62) found that childcare was even omitted from people's own recall of their work:

> No adult, whether male or female, includes infant or child care in his or her definition of work. ... Infant and child care appeared neither under work nor leisure. It is invisible.

In addition to the practical and emotional responsibility women take for caring for people within their family and social settings, they are frequently carers in the formal HIV/AIDS sector, either as nurses or volunteers and community health workers (Strebel, 1995; Wilson, 1992). In the formal health sector (independent of HIV/AIDS), women make up 75% of the labour force, typically in positions that are either poorly paid or unpaid (Strebel, 1995). Occupations dominated by women have lower earnings because they are seen as less important and requiring less skill, and it is therefore unsurprising that this work tends to be similar to the unpaid care work that women undertake in their homes (e.g.

childcare and housework) (UNAIDS, 2004b). In the context of HIV/AIDS, much of women's work is subsumed under the terms "community care" or "home-based care", with varying degrees of state or NGO support, thereby maintaining their social construction as "natural" carers and denying them the support and recognition they deserve (Schiller, 1993; Skhosana, 2003).

Perhaps more important for the present dissertation, is the recognition that many women adopt multiple roles in relation to the epidemic simultaneously. The large majority of women continue to participate in the 'care economy', carrying out unpaid care and other domestic work in the household even if they themselves are AIDS-sick or experiencing HIV-related symptoms (Steinberg et al., 2002; UNAIDS, 2004b). A large number of women, many of them with children, therefore negotiate the dual role of being HIV positive and being a caregiver, in addition to the economic demands placed on them by virtue of living in poor communities in which they are often responsible for meeting the survival needs of their households.

Women's gendered position requires them to do domestic labour caring for the sick, often taking them away from other productive household tasks and preventing them from replacing the lost income consequent on household providers' inability to work due to illness (UNAIDS, 2004b; UNAIDS, 2004c). In so doing, women often neglect their own physical and emotional wellbeing, including the challenges posed by physical symptoms (Armistead, Klein, & Forehand, 1995). Evidence to support this contention is the fact that some studies found a low orientation to health status among HIV-infected women for whom large numbers of children were a source of competing needs and interests (Karus, Siegel, & Raveis, 1999). Moreover, several studies report that mothers spend considerably more time caring for the needs of their affected and infected children than for themselves (Bunting, 2001; Rose & Clark-Alexander, 1996a).

The point of this discussion is not to construct women as victims or to deny that a great many demonstrate enormous resilience in the face of adversity, for there certainly is evidence to suggest that this is the case (for example, see Brandt, 2005a; Evans, 2005; Weinberg & Simoni, 2004). Further, it is also important to recognise that the role of mother and carer is one that many women value themselves (Kobayashi, 2000). Several

studies conducted in developed and developing countries have found that HIV-infected women have a particularly strong need to maintain their parental status, perhaps partly as a result of their internalisation of communal norms and values. Consequently, some women are reluctant to seek assistance or to give up their caregiving role despite their illness (Broun, 1996; Hackl, Somlai, Kelly, & Kalichman, 1997; Van Loon, 2000). As one woman explained, part of maintaining normalcy was being able to maintain the role of mother (Ciambrone, 2003; Sandelowski & Barroso, 2003). Being and remaining "normal", something which was clearly desirable for many of the women, was therefore equated both with being a mother and maintaining a fairly active caregiving role, as opposed to delegating caregiving responsibilities to others. Where women are less actively engaged in a caregiving role in relation to their children, or where caregiving is more shared as in some communities (Bray et al., in press), it is possible that a different situation would pertain.

What this discussion has attempted to argue and shed light on is the interrelationship between gender, HIV/AIDS and poverty, and the extent to which this context places women, carers and mothers at particular risk. As several writers have noted, HIV/AIDS for poor women is a qualitatively different disease to that identified at the beginning of the epidemic (among homosexual men in the United States) (Ward, 1993). The social climate in which the disease is transmitted, diagnosed and treated, and the resources with which the disease is experienced, are strikingly different (ibid), but just as important for poor women.

HIV is a new disease that reveals, parallels and exacerbates old health and social problems (Farmer et al., 1996; Ward, 1993). This is evident in the (limited) empirical evidence that shows that AIDS, in a country such as South Africa, is perceived as a part of a set of complex social problems and is not in fact singled out as the greatest or most immediate threat by either men or women living in endemic poverty (Kalichman & Simbayi, 2003b). As Carol Bellamy, Executive Director of UNICEF, stated in the report of the Secretary-General's Task Force on Women, Girls and HIV/AIDS in southern Africa:

> For some time now, it has been clear that women in Africa are buckling under the strain – besieged on one hand by high infection rates and on the other by the increased demands they face as caregivers and breadwinners (in UNAIDS, 2004c, p. 6).

Poor women and mothers infected with HIV experience poverty more acutely than before and face more responsibilities in their role as carers, both of which are fueled by their gendered identity and both of which place them at risk. In the next section of this chapter, a particular category of risk will be examined in more detail, namely, mental health.

1.3 POVERTY, MENTAL HEALTH AND HIV/AIDS

This section will present evidence to demonstrate that both poverty and HIV/AIDS contribute independently to mental health problems, in addition to other social and health problems. Further, the implications of the advent of highly active antiretroviral therapy (HAART) for the psychological consequences of HIV will be considered. It must also be noted that while the specific mental health implications of poverty and HIV/AIDS for women are the subject of Chapter 2, this section will present the links between these constructs more broadly.

1.3.1 Mental health in the context of poverty

1.3.1.1 The neglect of mental health and the burden of disease in developing countries

The neglect of mental health in developing countries is a long-standing phenomenon and one that has become more entrenched with every new public health challenge (Desjarlais, Eisenberg, Good, & Kleinman, 1995; Patel, 2005). The World Health Organization's (2001a) recent survey of mental health resources showed that 62% of low-income countries spend less than 1% of their national health budgets on mental health, and that beds per population and the number of mental health professionals are very low. Moreover, while private individuals are the primary source of mental health financing for 2.9% of high-income countries, they are the source for 40% of low-income countries' financing (ibid). More recent evidence of this neglect is the almost complete omission of mental health (and non-communicable diseases in general) in the Millenium Development Goals despite the fact that health-related issues make up three out of the eight goals (Miranda & Patel, 2005).

The neglect of mental health is typically justified with the argument that developing countries are burdened with many more serious physical health problems that require the majority of scarce resources (Miranda et al., 2005). However, there is clear evidence that mental health is an integral part of health and a significant contributor to disability and the burden of disease. A study conducted in 14 diverse World Health Organization (WHO) country sites demonstrated that mental illness is both an independent predictor of disability and functioning, and a stronger predictor than physical illness (Ormel et al., 1994). Global estimates indicate that mental disorders contributed to 10.5% of the burden of disease in 1990 (Murray & Lopez, 1996) and 12% in 2000 (World Health Organization, 2001b). Further, three neuropsychiatric conditions rank in the top 20 causes of disability adjusted life years (DALYs) for all ages, and six in the age group 15-44, while depression is the leading cause of disability worldwide (Murray et al., 1996).

The prominence of disease (in particular communicable, perinatal and nutritional conditions) in developing countries does mean that the proportion of mental health-related disability is lower than that in developed countries (World Health Organization, 2001b). However, neuropsychiatric conditions still account for 17.6% of all years lived with disability (YLD) in Africa (ibid). Globally, mental and neurological conditions account for 30.8% of all YLD (ibid). Mental and behavioural disorders therefore contribute significantly to both disability and morbidity in primary care settings (Patel & Kleinman, 2003). A wide range of figures have been reported, but it appears that between one in five and one in four people are affected by mental illness at some point in their lives, with the point prevalence for most disorders falling between 9 and 16% (Ormel et al., 1994; Patel et al., 2003; WHO World Mental Health Survey Consortium, 2004; World Health Organization, 2001b). Further, this finding has been corroborated in cross-cultural and socio-economically diverse primary care settings, with the most common diagnoses being depression, anxiety and substance abuse disorders (Ormel et al., 1994; World Health Organization, 2001b). What is perhaps as concerning as the high rates of mental illness in developing countries and the serious role impairment with which they are often associated, is the fact that they frequently go untreated (WHO World Mental Health Survey Consortium, 2004).

1.3.1.2 Poverty, mental health and gender inequality

In addition to the high prevalence and impact of mental illness in developing countries, there are several other associated features that are relevant to the present discussion, in particular gender inequality and poverty. With respect to the latter, there is considerable evidence that mental disorders are closely associated with poverty. In addition mental illness deepens poverty through the dysfunction, loss of employment and added medical expenses associated with severe psychiatric conditions.

According to Kohn et al. (1998 in World Health Organization, 2001b), the ratio for lifetime prevalence of mental disorder between the lowest and highest socio-economic status groups is 1.4:1. Further, in a review of community studies of mental illness since 1990, Patel and Kleinman (2003) report an association between poverty and common mental disorders in low- and middle-income countries. Only one study failed to find a significant relationship between mental health prevalence and several indicators of poverty, of which low education was most consistently associated. Other associated conditions include unemployment and income and material deprivation, as well as several other factors that present risks for poor physical health, namely, malnutrition, lack of access to clean water and inadequate housing (Patel et al., 2003; World Health Organization, 2001b). Poverty is therefore associated with a range of stressful life events which, in addition to personality, coping skills and genetic disposition, contribute to mental illness (World Health Organization, 2001b).

Given the link between mental health and poverty, and the evidence presented that women are most affected by poverty (Patel, Araya, de Lima, Ludemir, & Todd, 1999), it follows that some differences in mental health exist between men and women. With respect to severe mental illness, only depression is more prevalent amongst women (World Health Organization, 2001b). However, research on mental illness in general (and not only severe illness) in developed and developing countries shows that adult women have higher rates of depression and anxiety, and lower rates of substance use and antisocial personality disorders than men (ibid). Comorbidity is also more common in women, with depression,

anxiety and somatoform[8] disorders the most frequent presentation (ibid). Other gender factors discussed, for example, physical abuse from partners and fewer educational and job opportunities – all of which are also associated with poverty – are also likely to play a role in women's heightened risk for mental illness (Patel et al., 2003).

1.3.2 The relationship between mental health and HIV/AIDS

An as yet unmentioned part of the above analysis of mental illness and poverty is that HIV/AIDS – most prevalent in the poorest regions of the world – has also been associated with mental health in several ways[9]. To begin with, it may be instructive to outline the substance of the bi-directional relationship between HIV/AIDS and mental health. With respect to the pathway from mental illness to HIV, three important points should be mentioned. First, the presence of psychiatric disorders increases the risk for HIV infection, particularly through their association with risky behaviours such as unprotected sex (Treisman, Angelino, & Hutton, 2001). Evidence marshalled to support this argument is the high lifetime rates of mental illness in people testing positive for HIV (Perry et al., 1990), and the fact that many of the psychological disorders present in PLWHA preceded seroconversion (Catalan, Burgess, & Klimes, 1995; Gallego, Gordillo, & Catalan, 2000). Second, research into psychosocial predictors of treatment adherence suggest that poor mental health is a risk factor for non-adherence to antiretroviral therapy which negatively impacts on HIV outcomes (see, for example, Gordillo, del Amo, Soriano, & Gonzalez-Lahoz, 1999; Mellins, Kang, Leu, Havens, & Chesney, 2003; Murphy, Marelich, Hoffman, & Steers, 2004; Starace et al., 2002). Third, mental illness and poor psychological wellbeing can adversely influence disease progression by undermining immune functioning, a matter that is the subject of the field of psychoimmunology (see, for example, Panzer & Viljoen, 2002; Olley, 2003).

The focus of this discussion, and the dissertation as a whole, however, is the impact of HIV infection on mental health. Here what is relevant is the psychological experience of testing HIV positive and living with the disease and its associated social sequelae at each stage of

[8] This is the presence of physical symptoms not explained by physical disease.
[9] See Collins et al. (2006) for a recent review on mental health in developing countries in the context of HIV/AIDS.

the illness. A critical, or cautionary, note must however first be made regarding the available research in this area. As Kalichman (1995) points out, there are several problems with the early research in particular, which limit the comparability of findings and undermine the emergence of a rigorous and scientifically sound body of evidence. Many of the studies are exploratory in nature and methodologically limited, failing, for example, to include control groups of seronegatives (Gallego et al., 2000; Kalichman, 1995; Kalichman & Sikkema, 1994). Studies are also predominantly cross-sectional in design and do not always include participants at all stages of infection or a significant number of individuals with advanced infection (Gallego et al., 2000). The majority of studies, predictably, come from the United States (US) and United Kingdom (UK), meaning that participants are often white males and bi/homosexuals with medium to high levels of education or intravenous drug users. This limits the applicability of the research to large sections of the population living with HIV/AIDS in developing countries (ibid). A further difficulty is comparing studies that pre-date changes to the definition of AIDS in 1993[10], or the era of HAART[11] that began in the US in 1996 with the move away from monotherapy as the treatment of choice for HIV infection (Kalichman, 1995; Kalichman et al., 1994). Finally, self-report instruments in particular can present measurement problems as they tend to confound indicators of depression and anxiety with symptoms of HIV disease, for example, fatigue, weight loss and loss of libido (ibid). (This point will be discussed in more detail in the following chapters – see sections 3.3.3.3 and 4.2.1.)

1.3.2.1 A disease stage model of the mental health impact of HIV infection

However, despite these methodological limitations, there are several findings that contribute substantially to our understanding of the mental health impact of HIV infection. Generally, the large majority of people cope relatively well, both with receiving a positive diagnosis and living with the disease. A minority experience psychological problems at

[10] In 1993, the Centre for Disease Control (CDC) in the United States expanded the clinical definition of AIDS to include those with a CD4 cell count of less than 200. Another change that will be discussed further later was the addition of clinical conditions more common in women that were previously excluded (Stern, Perkins, & Evans, 2000).

[11] While it was important in earlier years to distinguish between monotherapy drug regimens and the triple cocktails that constitute highly active antiretroviral therapy, the current acceptance and dominance of HAART in the medical community has resulted in the use of ART and HAART interchangeably. Similarly, in this dissertation, the term ART (antiretroviral therapy) or ARVs (antiretrovirals) will sometimes be used for ease of expression. However, whenever monotherapy is not specified, HAART is implied.

some stage and an even smaller number severe psychiatric difficulties (Catalan et al., 1995; Treisman et al., 2001). For many, the response to the initial diagnosis is akin to an acute stress reaction (Kalichman, 1995). Intense and even severe distress is experienced, including feelings of shock, denial, guilt, self-pity and fear of imminent death. However, this distress is usually self-limited and of mild to moderate severity (Catalan, 1999; Gallego et al., 2000; Treisman et al., 2001).

In many ways the reactions to this and other stages of the disease are similar to other life-threatening physical conditions, except that the associated stigma and discrimination is much greater and the social context is one of increased vulnerability to psychological problems – since these are often individuals who live in poverty and/or come from socially disadvantaged, at-risk groups (Catalan et al., 1995; Kalichman, 1995; Treisman et al., 2001). For those who previously used denial and avoidance and only test in the symptomatic phase (as is the case in many developing countries such as South Africa), the risk may be greater (Catalan, 1999; Kalichman, 1995).

For those who test during the asymptomatic stage, this is the time to come to terms with the diagnosis and its impact on their lives, including reassessing roles and priorities (Catalan, 1999; Catalan et al., 1995). Distress is usually mild, with adjustment disorders, depression, substance misuse and sexual dysfunction the most common problems (ibid). As the illness progresses, and individuals struggle increasingly with pain and disability (Treisman et al., 2001), there is more consistent evidence of higher levels of psychological morbidity compared with both controls and asymptomatic individuals (Catalan et al., 1995; Maj et al., 1994). Some studies even suggest that the risk for mental illness may be greatest in this stage, more so than in AIDS patients who may in fact be less distressed than both asymptomatic individuals and those in the early symptomatic phase (Catalan, 1999; Kalichman, 1995). However, this does not negate the fact that anger and guilt, fear of how s/he may die, fear of loss of control and dignity, and loss of hope are significant elements of the final stages of illness (Catalan et al., 1995). While adjustment disorders, major depression and increased substance use are common in the symptomatic phase, organic brain syndromes (including delirium and dementia), psychotic illness and behavioural problems are most common in the final stage (ibid).

1.3.2.2 The course and prevalence of specific mental disorders in HIV infection

Epidemiological research examining the course and prevalence of mental disorder in HIV infection has also been conducted. One review paper suggests that between 38 and 73% of PLWHA have at least one lifetime mental disorder, with most preceding seroconversion, as noted above (Gallego et al., 2000). Nonetheless, a study on psychiatric morbidity on entering an HIV clinic found that one in two people reported significant levels of distress (based on self-reports of depressive and other related symptoms) (Lyketsos, Hanson, Fishman, McHugh, & Treisman, 1994; Lyketsos, Hutton, & Fishman, 1996).

One category of mental disorder is the organic type that is aetiologically related to the impact of the virus on the brain. Neurological impairment, most commonly cognitive decline, occurs either due to the direct effect of the virus on the central nervous system (CNS) or due to AIDS-related opportunistic infections against which the immune system cannot defend (Baingana et al., 2005). Significant cognitive decline is typically associated with advanced disease, with about 50% of AIDS patients experiencing some form of cognitive impairment (Baingana et al., 2005; Kalichman, 1995; Stern et al., 2000). However, the most severe form of impairment, AIDS-related dementia[12], occurs in between 8 and 20% of AIDS patients (Baingana et al., 2005; Maj, 1996b; WHO Consultative Meeting, 1990 in Catalan & Burgess, 1996). Cognitive slowing is the most commonly observed symptom (Kalichman, 1995). AIDS dementia is also the first AIDS-defining illness for as many as 25% of patients, while another 15% develop it along with other features of AIDS (Stern et al., 2000). Less severe cognitive deficits are more common, occurring in 30-60% of advanced cases, and are typically associated with minimal impairment in functioning (Kalichman, 1995; McDaniel, Purcell, & Farber, 1997).

CNS damage can also result in delirium, mania or psychosis, the most common sources of psychiatric referral and hospitalisation in critically ill AIDS patients. While delirium occurs in 43-65% of late-stage individuals, psychosis is much less common at 0.2-15% (Baingana et al., 2005; Gallego et al., 2000; McDaniel et al., 1997; Stern et al., 2000). New

[12] This condition is also referred to as AIDS Dementia Complex, HIV associated dementia or HIV associated cognitive motor complex (Stern et al., 2000).

onset psychosis in the absence of personal or familial history is a poor prognostic indicator associated with slow cognitive decline and reduced survival (Catalan et al., 1995), as is mania which occurs in 8% of patients, also in the late stage (Baingana et al., 2005; Gallego et al., 2000). Both conditions tend to be more severe and chronic than mania or psychosis not associated with organicity (Fishman & Lyketsos, 1996). Other organic disorders are (rare) secondary mood syndromes, and medical conditions such as Kaposi's sarcoma and cerebral toxoplasmosis that manifest with psychological symptoms (McDaniel et al., 1997).

Among the non-organic psychiatric disorders, adjustment disorders and major depression are the most commonly reported and diagnosed clinical syndromes, affecting as many as 60% of PLWHA at some point in the illness (Collins, Freeman, & Patel, 2006; Fishman et al., 1996; Kalichman, 1995; Treisman et al., 2001). It has been reported that PLWHA (at any point in time) present with rates of depression similar to those in other medical populations but higher than general primary care patients (4-14%) (Ciesla & Roberts, 2001; Rabkin, 1996), and that they are twice as likely to suffer from depression as the general population (Baingana et al., 2005; Ciesla et al., 2001). It may be that higher reported rates are a function of the high risk groups studied, particularly homosexual men who have been found to have elevated levels of depression regardless of their HIV status (Maj, 1996a; Perkins et al., 1994; Rabkin, 1996; Rabkin, Ferrando, Jacobsberg, & Fishman, 1997; Rosenberger et al., 1993). Moreover, Rabkin (1996) reported that 80% of those seeking treatment for depression had a history of depression predating seroconversion. Risk for suicide has also been reported to be elevated, as much as 7 to 36 times that in a matched population (Catalan et al., 1995), and is likely to be predicted by HIV-specific factors as well as previous suicide attempts or serious psychiatric history (Kalichman, 1995).

Substance use disorders and sexual dysfunction are also amongst the most commonly reported psychiatric complaints in infected populations. The prevalence of substance use has been reported at 20-73% (Baingana et al., 2005; Gallego et al., 2000; Lyketsos et al., 1996; Rabkin, 1996), although current rates are reported as much lower. Sexual dysfunction is particularly common in the symptomatic phase or when new treatment is started, but can also result from pre-existing difficulties or a psychological response to

diagnosis and infection (for example, fear of infecting one's partner) at other stages of the disease (Catalan et al., 1995; Gallego et al., 2000). Uncertainty regarding the illness is a key contributor to anxiety, but levels average 5% and are not generally higher than in community samples (Kalichman, 1995; Rabkin, 1996). Personality disorders, somatisation and hypochondriasis have also been reported and can complicate the process of adapting to, and coping with, HIV (Baingana et al., 2005; Kalichman, 1995).

1.3.2.3 General risk factors for psychological morbidity

While it is possible to delineate mental health symptoms as a function of disease stage, and to state the prevalence of particular conditions, Kalichman's (1995, p. 156) observation is an important one: "rather than a linear progression, psychological reactions to HIV infection represent cycles of emotions usually initiated by HIV/AIDS related events". Moreover, the particular pattern and nature of responses are determined by a range of factors, some of which have already been discussed.

Medical events or HIV-related factors are one such risk category, and include receiving a diagnosis of HIV, the development or worsening of symptoms, being diagnosed with AIDS, and hospitalisation (Catalan, 1999; Catalan et al., 1995; Gallego et al., 2000; Kalichman, 1995; Lyketsos et al., 1994). Related factors are the uncertainty regarding treatment efficacy, and dealing with the uncertain course of illness and constant reminders of the disease, including symptoms and daily medication regimens (Kalichman, 1995).

Other factors that play a role in predicting morbidity are the nature and quality of social supports, personality traits and the choice of coping strategies (Catalan, 1999; Catalan et al., 1995; Gallego et al., 2000; Kalichman, 1995); perceived responsibility and cultural scripts regarding the expression of distress (Kalichman, 1995); and the experience of social losses (either partners, friends and employment or losses due to AIDS) (Gallego et al., 2000; Kalichman, 1995; Sherr, Hedge, Steinhart, Davey, & Petrak, 1992). Past psychiatric history is a particularly strong predictor, partly since pre-existing mental health problems (including substance use) are present in many groups most affected by HIV, along with poor health resources, congested conditions, and care burden in the case of infected women and mothers (Kalichman, 1995; Lyketsos et al., 1994; Lyketsos et al., 1996; Perry &

Fishman, 1993). The argument has already been made that these poverty and gender-related factors are in and of themselves risk factors for poor mental health, in addition to being associated with high HIV prevalence. The fact that these groups are also likely to be the target of HIV-related stigma and discrimination further complicates attempts at psychological adjustment by causing chronic stress, complicating disclosure, undermining coping and social support, and sometimes resulting in social withdrawal, all of which can contribute to persistent distress and mental health problems (Kalichman, 1995).

1.3.3 Mental health and poverty in the era of HAART

With the advent of HAART, available in the US since 1996, it was fairly widely assumed that both the physical and mental health impact of HIV/AIDS would be significantly ameliorated (Siegel, Karus, & Dean, 2004). In 1999, Catalan stated that:

> There is at present a feeling that the textbooks will have to be rewritten soon and that what was thought to be certain knowledge (of the adverse *psychological* and social consequences of HIV) will be shown to be less solid than expected (Catalan, 1999, p. 21; emphasis added).

Further, Rabkin and Ferrando (1997) used the term 'second life agenda' to refer to the renewed hope and optimism experienced as a result of HAART which, for the first time, signaled the possibility that HIV would be a treatable chronic illness rather than a disease that signalled imminent death.

However, the prospect of extended survival presents significant psychosocial challenges – some old challenges in a different guise and some new ones associated with managing a chronic illness. With respect to treatment, antiretroviral therapy has side-effects and requires (sometimes) complicated regimens to be taken daily for life (Department of Health, 2004; Kalichman, Ramachandran, & Ostrow, 1998). Further, at least 95% adherence is needed to ensure sufficient viral suppression to avoid the development of treatment resistance. This is likely to be particularly important in developing countries where less treatment options are available in the event that resistance to firstline treatments develops. Despite the promise of new drug regimens, there was also considerable uncertainty regarding long-term treatment safety and efficacy, particularly at the time of

their emergence (Catalan, Meadows, & Douzenis, 2000; Siegel & Lekas, 2002). Inadequate patient education may result in greater distress in the event of treatment failure (Kalichman et al., 1998; Rabkin & Ferrando, 1997). Drug interactions are also likely, including with psychotropic medication used to treat mental health problems, resulting in complex management issues and possible lessening of therapeutic effects (ibid). Some have also pointed to the implications of widespread availability of HAART for prevention efforts, suggesting that perceptions of reduced risk of transmission for those on treatment could result in an increase in high-risk sexual behaviour (Catalan et al., 2000; Kalichman et al., 1998)

In addition to treatment-related factors, people on HAART are faced with other challenges, key amongst which is the need to reevaluate their life and renegotiate roles and relationships. This may involve returning to work, renewing old relationships, contemplating new intimate relationships, and negotiating shifts in role as a result of improved health (Kalichman & Ramachandran, 1999; Siegel et al., 2002). For women, treatment access may provide renewed hope regarding the prospect of parenthood. However, despite optimism, such changes can be associated with renewed anxiety regarding stigma and disclosure, and concerns regarding employability and the health implications of added stress on return to work. Further, sexual dysfunction is a possible side-effect of treatment, and can greatly complicate an attempt to resume or begin new intimate relationships (Catalan et al., 2000). These factors, together with the need to take daily medication, may be a constant reminder of the patient identity that challenges individuals in their attempt to positively reframe their concept of living with HIV (Siegel et al., 2002).

1.3.3.1 Empirical evidence regarding the psychological impact of HAART

While several published empirical studies (in developed countries) include participants on HAART, few have systematically explored the mental health and psychosocial implications of the availability of, and access to, treatment. Further, of this handful of studies, the majority have included only homosexuals and/or men. Two such studies, both of which followed a cohort for two years, found improvements in psychosocial wellbeing associated with HAART. While Rabkin et al. (2000) found a clinically modest (but

statistically significant) reduction in distress in a cohort of bi/homosexual men with symptomatic illness, Judd et al. (2000) reported a decrease in depression and number of stressful life events in relatively asymptomatic adults (most of whom were intravenous drug users and/or homosexual). Further, Catalan and colleagues (2000), in a review of patients at a London psychiatric service for PLWHA, found a decrease in adjustment disorders, organic brain syndromes and mania throughout the 1990s, a period during which access to treatment became more common. Rates of depression and anxiety, however, increased, as did sexual dysfunction. A more recent study that included 80% men reported significant increases in quality of life from baseline to 12 months, including improved mental health, with those with lower baseline CD4 counts showing the greatest improvements in overall mental health (Mannheimer et al., 2005).

Other qualitative studies with (mostly) homosexual men have, however, pointed to a range of difficulties associated with HAART, including uncertainty regarding negotiating social roles and interpersonal relations (Bogart et al., 2000; Brashers et al., 1999), uncertainty about returning to work (Brashers et al., 1999; Lee, Solts, & Burns, 2002), and anxiety regarding treatment and the perceived intrusiveness of medication that serves as a daily, visible marker of illness (Lee et al., 2002). Further, amongst a matched sample of women (75% of whom were mothers) in the pre- and post-HAART eras, women in the post-HAART era were more likely to report health-related stress and stress from stigma and disclosure, to view HIV as causing them harm, to report that their health is due to chance, and to use avoidant and emotion-focused coping strategies (Siegel & Schrimshaw, 2005). They also exhibited generally poorer adjustment to their illness in the home environment (Siegel et al., 2004) This difference is attributed to higher expectations amongst women in the HAART era (leading to more stress when problems arose), but also possibly to ongoing, chronic non-HIV related stressors in their lives.

While the results are not conclusive, taken together they suggest that treatment may change the nature of psychosocial and psychiatric problems rather than prevent them altogether. Focus is likely to shift from anxieties regarding the short-term to concerns about the long-term. Further, difficulties might be particularly marked for PLWHA who have been very ill and dysfunctional prior to commencing treatment (as opposed to relatively asymptomatic).

Such individuals may experience more real and perceived difficulties in managing their lives with the illness in the long-term (Michaels, Hildebrand, Boulle, & Darder, 2005).

1.3.3.2 Developing country access to HAART

Of course a very important caveat to this discussion is the fact that, whether HAART improves or complicates mental health outcomes, not all PLWHA have access to treatment. While progress has been made through the vehicle of the WHO's '3x5' campaign[13], only one in ten Africans and one in seven Asians in need of HAART were receiving it in mid-2005 (UNAIDS, 2005). Half of all people in developing countries receiving HAART live in sub-Saharan Africa, yet coverage in this region was still only at 11% in mid-2005 (UNAIDS, 2005; World Health Organization, 2005a). Further, progress has been uneven. Thus while coverage in Botswana and Uganda is around 33%, 90% or more of those in need in Ethiopia, Ghana and Mozambique are still not receiving treatment (UNAIDS, 2005).

In South Africa, despite being home to one in four HAART recipients in sub-Saharan Africa, coverage remains relatively low. UNAIDS (2005) figures for mid-2005 put coverage at 15%, while estimates for mid-2006 released by the Actuarial Society of South Africa suggested improved national coverage of 30% (Department of Health, 2006e). By September 2006 (the most recent figures available at the time of writing), 213 828 people in South Africa were receiving HAART as part of government's 2003 Comprehensive Plan[14] to roll-out HAART in the public sector[15] (Department of Health, 2006b).

While public sector coverage in South Africa increased by 85% from the end of 2005 to September 2006, the total number of cases on ARVs was still only 33% of the 2006/2007 target set in government's 2003 plan (Department of Health, 2003; 2006c). Further, HAART coverage is uneven, with successes in some provinces bringing up the national

[13] This campaign aimed to provide access to treatment for three million people in developing countries in need of HAART by the end of 2005.
[14] The 'Broad Frame-work for HIV & AIDS and STI Strategic Plan for South Africa 2007-2011 (NSP)' was released in November 2006 at the time of writing. When finalised and adopted by the reconstituted South African National AIDS Council (SANAC) in March 2007, it will supercede the Comprehensive Plan.
[15] Private sector health services' serve only a minority group, leaving the majority of South Africans who live in poverty reliant on the public sector to meet their health care needs.

average (for example, the Western Cape which reached its target in mid-2004), while other provinces continue to lag behind targets considerably (Department of Health, 2006c; Nattrass, 2006a). However, for the purpose of the present discussion it must be noted that 70% of the patients at the country's first public sector HAART programme in Khayelitsha (Cape Town) were women (Coetzee et al., 2004). For reasons that will be discussed below, women in Africa (and South Africa) tend to have more access to HAART than men since many referrals continue to come through antenatal services (Boulle, 2003; UNAIDS, 2004c).

1.4 THE CATEGORISATION OF WOMEN IN HIV/AIDS DISCOURSE AND PRACTICE

Before considering the implications of the aforementioned discussion on women, HIV/AIDS, poverty and mental health, a brief analysis of the categorisation of women in HIV/AIDS discourse and practice is in order.

Two processes in particular seem to be at play simultaneously, what Squire (1993a) has referred to as overgendering and undergendering. Women are either ignored and marginalised, or pathologised in ways that mirror some of the dominant cultural definitions to which this chapter has already referred. More specifically, where women are referred to it is as vectors of the disease, either the sex workers that infect men or the mothers that transmit the disease to their unborn children (Berer & Ray, 1993; Cohan & Atwood, 1994). The construction of women as pollutants, deviants and the incarnation of sexual danger and biological power are therefore reproduced despite the fact that men are permitted multiple partners (a risky sexual practice), without questioning how the sex worker herself became infected, and despite growing evidence of women's own vulnerability (Anastos & Marte, 1990 in Cohan et al., 1994; Berer & Ray, 1993; Lawless, Kippax, & Crawford, 1996; Ogden & Nyblade, 2005; Squire, 1993a; Upton, 2003). In a similar vein, debates regarding the reproductive choices of HIV-infected women focus on women's behaviour while ignoring men's role or responsibility in decision making (Strebel, 1995). For women from socially disadvantaged groups (often those most affected by HIV/AIDS), these forms of marginalisation can be heightened as their gender intersects with ethnicity and class to

create multiple vulnerabilities or avenues of risk (Bredstrom, 2006; Gupta et al., 2003; Worth, 1990).

There are several practical consequences of the construction of women in AIDS discourse, including a historical neglect of the effect of the illness on women themselves (Cohan et al., 1994). Long after there was evidence that women were susceptible to HIV, it remained constructed as a gay man's disease and most research, including drug trials, were conducted either predominantly or exclusively with men. This led to implicitly male models of disease and non-specific, even clinically inappropriate treatment and therapeutic approaches for women (Cohan et al., 1994; Hankins & Handley, 1992; O'Sullivan & Thomson, 1992; Squire, 1993a; Strebel, 1995). Even the definition of AIDS was derived from research with men, with conditions that tended to affect or were unique to women, such as invasive cervical cancer, recurrent pneumonia and pulmonary tuberculosis, only added to the definition of AIDS just more than ten years into the epidemic in 1993 (Cohan et al., 1994; O'Sullivan & Thomson, 1992). Consequently, cases in women were underreported and tended to be diagnosed later, and women frequently started treatment later when they were more ill (Strebel, 1995). Given that the manifestations of the disease were less well understood in women, as was the effectiveness of drugs and their potential side-effects, clinical management of women on treatment was also undermined (Cohan et al., 1994)

The marginalisation of women in AIDS discourse has also been evident in at least three other related ways. First, women's issues received limited coverage at international AIDS forums, with the first coverage occurring at the seventh international AIDS conference in 1991 and the first 'Women's Track' with a special programme in 1992 (Long, 1996; Sherr, 1996). Where women were included in international agendas they continued to be treated only as those who passed on the infection as mentioned above (ibid).

Second, women-centred or gender-specific issues were slow to become the focus of global research, policy and service organisations. The United Nations Development Fund for Women (UNIFEM) and the International Centre for Research on Women (ICRW) had already been formed in 1976, and a regional community-based organisation on women and AIDS in Africa (The Society for Women and AIDS in Africa - SWAA) was formed in

1988. However, it was only in 2004 that the UNAIDS formed the Global Coalition on Women and AIDS. Twenty years into the epidemic, this was a recognition of the need to respond to "the increasing feminisation of the AIDS epidemic and a growing concern that existing AIDS strategies did not adequately address women's needs" (http://womenandaids/unaids.org).

Third, and perhaps surprising, is the fact that even feminist leaders and activists were slow to focus attention on women and HIV/AIDS, having failed to do so for much of the first decade of the epidemic (Treichler & Warren, 1998, p. 119).

More recently, however, increasing global attention has been focused on women and HIV/AIDS, and a growing academic literature is also available. In a 1996 paper, Sherr reported that a search of the Medline database revealed that the considerable increase in publications on HIV/AIDS in general from the period 1985-1990 to 1991-1995 was not mirrored in publications on women and HIV/AIDS. Further, the proportion of publications on women remained low at 4.1-7.5%. Beyond the time of Sherr's writing, some improvements should be noted.

By way of example, since the first well-documented book on women and AIDS, Diane Richardson's 'Women and the AIDS crisis', was published in 1987, at least 25 books have been published by social scientists and women living with HIV/AIDS that focus specifically on women and gender issues. These have covered a range of topics including: the invisibility of women in the epidemic (Corea, 1992); the psychological concerns of Western women affected by HIV (Squire, 1993b); the need for feminist theory and practice (Doyal, Naidoo & Wilton, 1995) and gender-sensitive interventions and policies for women (Long & Ankrah, 1996); and broad-based overviews of the gendered psychological, medical and social ramifications of AIDS across different population groups and societies (Sherr, Hankins, & Bennett, 1996). Most recently, women's everyday experiences of the impact of the disease on their lives has received attention, including how they work to 'mend their fractured selves' (Ciambrone, 2003). It is perhaps significant that a large number of these edited and single-authored volumes were published in the mid-1990s, following the change in the definition of AIDS to include women-centred syndromes.

It is certainly not accurate to characterise the research, policy and service arena as having completely failed to address women's issues until very recently. However, the point to be made is that there is clear evidence of the marginalisation of women's issues, particularly in the first ten to twelve years of the epidemic (1981-1991/3), as well as the problematic representation of their roles and experiences in general. Further, there has been a growing historical shift subsequently toward not only more attention, but more appropriate attention, to matters concerning women. Nonetheless, in relative terms, the gaps and omissions very clearly remain. Just as Reynolds (1991, p. 159) stated that children are "all too often ... lumped in that amorphous category 'women and children'", the corollary is true that women have been "lumped" in that category and not often treated as analytically separate. Women continue to be emphasised in terms of what they are to other people, in particular mothers and wives/partners (Hogan, 1998), and thus the lens seldom falls on their experience per se.

1.4.1 The relevance of mental health for HIV-infected women and mothers living in poverty

For the purpose of the present dissertation, two particularities of this failure are relevant: first, poor women and AIDS are still largely neglected despite the growing number of publications (Farmer, Connors, Fox, & Furin, 1996); and second, the wellbeing and mental health of women, including but not exclusively those living in poverty, is especially neglected. Issues of class, social context and poverty are either absent or glossed over in the few psychological theories of the impact of HIV/AIDS, activist literature and much feminist literature (ibid). Moreover, mental health, including that of women, remains low on the agenda of developing countries even in the era of HIV/AIDS.

Given the arguments presented in this chapter, the position taken is that the gap with respect to the mental health of HIV-infected women and mothers living in poverty, particularly those in developing countries for whom access to HAART is less likely to be a given, is one that merits addressing. Living in such circumstances, and dealing with the multiple stressors associated with poverty, HIV and childcare, quite clearly places these women at increased risk for mental health problems for all of the reasons already discussed. In addition to the challenges which living with HIV and being a caregiver places

on women in middle-class societies, women living in developing world settings must negotiate these challenges against the backdrop of adverse social and environmental conditions. Further, even where HAART is available, it has been argued that mental health concerns remain as relevant as before.

CHAPTER 2. REVIEW OF THE LITERATURE: THE PSYCHOLOGICAL AND PSYCHOSOCIAL FUNCTIONING OF WOMEN AND MOTHERS INFECTED WITH HIV/AIDS

Chapter 2 presents a review of the literature on the psychological adjustment of women and mothers infected with HIV/AIDS. As noted earlier, this is intended to serve as an adjunct to the policy context considered in Chapter 1 in order to frame the study's particular objectives and contributions.

The chapter will be structured as follows: To begin with, the parameters of the review and the methodology used to source the literature will be articulated. Within the review, available research on the prevalence of psychiatric disorders and psychological symptoms in HIV-infected women will be presented first, followed by an examination of the role of health and non-health related predictors of adjustment. Three specific predictors, namely, social support, coping and disclosure, will also be discussed in more detail due to their centrality within the literature.

Second, the review will consider mothering and other care roles in the context of HIV/AIDS as they pertain to women's psychological adjustment. Third, other broader psychosocial issues and problems that emerge in the literature from both quantitative and qualitative research will also be discussed. Fourth, given the dearth of available research in Africa and South Africa, and its relevance to the present study, this literature will be discussed in slightly broader terms than other literature reviewed. As argued in Chapter 1, the epidemic of poor women that concerns this study is an African, and even a southern African, one. Further, John Iliffe (2006) has demonstrated in his history of the African AIDS epidemic that there are important reasons for examining this epidemic as separate from that in the rest of the world. The literature from Africa therefore has much greater applicability to the present study than that from either developed or developing countries beyond the continent (Greenblatt et al., 2000; Iliffe, 2006; UNAIDS, 2006).

Finally, the last section of the chapter will critically examine the research gaps and opportunities, given the findings of the review and the context set up in Chapter 1. The study's specific aims and contributions will be articulated in light of these gaps and opportunities.

2.1 REVIEW METHODOLOGY

The review draws on both published and unpublished English-language material up to and including 2006 that was largely identified using keyword searches of electronic databases. The main keywords used were "HIV/AIDS" and "women" or "mother", with "care" ("caregiver" or "caregiving"), "psychosocial" or "mental health", "depression" or "anxiety", "stigma" or "disclosure", and "social support" or "coping" as specifiers. A wide range of social science and medical online databases were sourced and additional papers were identified by scanning the reference lists obtained through these sources. The databases sourced were: PsycINFO, PsycARTICLES, Academic Search Premier, AIDSearch, Medline, Family and Society Studies Worldwide, Sociological Abstracts, Ebsco Electronic Journals Services, Science Direct, ISI Web of Science, ProQuest, PubMed, Index to South African Periodicals (ISAP) and South African ePublications. A limited amount of additional grey literature or papers in progress or in press at the time of writing was also obtained by contacting key researchers in the field. While single case reports are not included, studies based on more extensive reviews of clinical case files are reported.

2.1.1 Conceptual parameters

This study had several conceptual parameters which are important to note. First, this dissertation focuses on the psychological experience of living with a positive HIV diagnosis but not on other pathways of influence between HIV/AIDS and mental health. Consequently, issues such as anticipatory anxiety prior to serostatus testing or the impact of poor mental health on disease progression are beyond the scope of this dissertation.

Second, mothers/caregivers and not mothers-to-be are the focus of this review. Some of the issues discussed in the review may also pertain to the experience of HIV-infected pregnant women. However, others may not and still other aspects of pregnant women's experience are unique to this group and will therefore not be revealed by the present review[16].

Third, the review does not deliberately cover the psychological implications of other chronic illnesses. This is a large and substantial field in and of itself that is beyond the scope of the present study. However, it is worth noting that cervical cancer, as one chronic disease, can manifest as an opportunistic infection in HIV-infected women. Moreover, there is good evidence that an HIV diagnosis has different implications to that of other chronic diseases such as cancer and diabetes.

Fourth, the review focuses on the psychology of women only and on women who have been infected through heterosexual transmission since this is the predominant mode of transmission for women living in poverty in sub-Saharan Africa. This is what is typically referred to as a generalised epidemic that can spread on its own in the general population if unchecked (Department of Health, 2006a), as opposed to one that predominates in at-risk groups such as sex workers, men who have sex with men (MSM), and intravenous drug users (IVDU). Consequently, psychological studies that focus *exclusively* on bi/homosexual men and women, intravenous drug users or those infected via sharing of blood products are not included in this review. However, where the study sample includes MSM and/or IVDU participants, but where the focus of the studies is not on these populations per se, they are included. A few studies that compare the functioning of men and women or IVDU and non-IVDU have also been included where they allow for findings to be disaggregated according to sex/gender and mode of HIV transmission, and hence for comparison with studies conducted with non-IVDU women.

[16] Three studies that report on the mental health of mothers of infants were, however, included. Miles et al.'s (2001; 1997) work followed mothers (and their children) from birth to 2 years, while Smith et al.'s (2001) and Bennett et al.'s (1999) studies investigated mothers 2-6 and 18-24 months post-partum, respectively.

2.1.2 Methodological issues

A few comments regarding the methodology of reviewed studies are in order. Several points regarding available research were already made in Chapter 1, including the limitations created by the use of narrow sampling approaches and self-report instruments, and predominantly cross-sectional designs without controlled comparison groups (Gallego et al., 2000; Kalichman, 1995; Kalichman et al., 1994). Also, not all studies provide detailed information regarding participants' stage of illness or CD4 count, and many do not indicate whether participants were receiving antiretroviral medication at the time of the study.

While systematic data on these issues is not always available, some general points are worth mentioning. With regard to the availability of treatment, most data gathered in the US post-1996 is likely to include a substantial number of participants on triple combination therapy (Siegel et al., 2004). The same is not true for studies conducted in developing countries where HAART is much less widely available, if at all. With regard to stage of illness, HIV-infected asymptomatic mothers (and caregivers) comprise approximately 50 percent of the total in the majority of studies, followed by symptomatic mothers and mothers who meet the criteria for AIDS. Where the differential impact of stage of illness has been explored, this will be noted. However, in several cases, such analyses were not undertaken and even where they were, changes to the definition of AIDS in 1993 further limit comparisons. Some other differences across study samples, for example, the average age of participants and the average time since diagnosis, limit comparability to a much lesser extent and are often considered as covariates, particularly in multivariate analyses.

One final point with regard to context is that the majority of (English-language) papers sourced draw on samples of North-American women and mothers. Thus, rather than referring to the context of each study, context will be specified where it is relevant to the comparison or synthesis attempted, and to draw attention to the minority of studies conducted outside of the US. Mention is also made of the locality of four developing country studies from outside of Africa that are reviewed, namely Bennetts et al.'s (1999) research in Thailand, Majumdar's (2004) work with women in India, and Tostes, Chalub and Botega's (2004) and de Mello and Malbergier's (2006) work in Brazil. As noted

earlier, studies conducted in Africa or South Africa will be reviewed separately due to their limited number but particular relevance to the task at hand.

The key point to be made is that the differences in method, context and population evident in the literature considerably limit the comparability of findings. Further, it is the combination of these characteristics that renders the knowledge base fairly diverse and fragmented at times. Consequently, repeated reference to the methods of reviewed studies has been necessary in order to adequately reflect the state of the field. In one section, a box has been used in order to review these issues while retaining the intelligibility of the substantive findings that emerge across the literature.

2.2 PSYCHIATRIC MORBIDITY AND PSYCHOLOGICAL WELLBEING

The first published (English language) study to examine the psychological adjustment of HIV-infected women specifically, as opposed to PLWHA in general, was conducted by Brown and Rundell in the US and published in 1990. This was nearly ten years into the epidemic and years after a body of literature had emerged examining mental health amongst infected men, most of whom were homosexual and living in the US. Studies that followed were: Franke, Jager, Thomann and Beyer's 1992 study in Germany, Pergami and colleagues' Italian study in 1993, and a follow-up paper by Brown and Rundell also in 1993. In 1994, a study was published in the US (Linn, Anema, Estrada, Cain, & Usoh, 1994) as was one conducted in London and Paris (Mellers, Marchand-Gonod, King, Laupa, & Smith, 1994).

Given the nature of the epidemic at the time, it is unsurprising that only one of the above-mentioned studies, that of Linn and colleagues (1994), has substantive relevance for the majority of infected women in the present day since it was conducted with low income, predominantly African American women. The three European studies sampled mostly IVDU, and the US study, while marking an important beginning, draws on a highly specific sub-population, white, employed women affiliated with the US Air Force. Further, at least half of the women in Brown and Rundell's (1990; 1993) study were employed at

the time of the research, a very different group to the majority of infected women currently, most of whom live in poverty and are unemployed.

It was only in the late 1990s that the number of published papers began to increase. Despite the increase, the body of scientifically sophisticated work (for example, studies employing control groups and non-convenience samples) of relevance to the large majority of HIV-infected women in 2007 remains comparatively small given the long-standing nature of the epidemic and the importance of these questions. There is nonetheless a substantial amount of evidence to be considered with regard to both the extent of mental health problems and the factors that render women vulnerable to poor mental health.

2.2.1 Rates and levels of psychiatric disorder and psychological symptoms

2.2.1.1 Prevalence of psychiatric symptoms and disorders

Taken as a whole, the available evidence points to high levels of psychiatric morbidity and psychological symptoms[17] amongst HIV-infected women, many but not all of whom are mothers.

Aside from papers based on clinical case reviews (Sherr et al., 1997; Taylor, Amoodei, & Mangos, 1996), only two relatively small scale studies used a clinical interview: Brown and Rundell (1990; 1993) in conjunction with a standardised self-report scale (n=43), and Wood and Tobias (2004) as a stand-alone tool (n=40). Only one study did not employ a standardised or clinically established method, instead devising its own set of screening questions (Gielen, McDonnell, O'Campo, & Burke, 2005).

Of the thirty non-case review studies on prevalence included (three of which sampled men, but reported rates disaggregated according to sex), eight included control groups. Six studies focused on women only as well as including control groups (Catalan et al., 1996;

[17] Where the review refers to levels of symptoms and distress, the data is based on standardised self-report scales such as the Centre for Epidemiologic Studies Depression Scale (CES-D), the Hospital Anxiety and Depression Scale (HADS), the Symptom checklist (SCL) and the Brief Symptom Inventory (BSI). The prevalence or rates of clinical disorders or psychiatric morbidity are based on standardised diagnostic tools such as the Structured Clinical Interview for the DSM (SCID), the Clinical Interview Schedule (CIS) and the Composite International Diagnostic Interview (CIDI).

Johnson & Lobo, 2001; Morrison et al., 2002; Pergami et al., 1993; Richardson et al., 2001; Tompkins, Henker, Whalen, Axelrod, & Comer, 1999); three of these studies drew on sample sizes of 100 or more (Morrison et al., 2002; Richardson et al., 2001; Tompkins et al., 1999). Two longitudinal studies on HIV-infected women were reviewed, one a large-scale study (n=871) (Milan et al., 2005) and another a much smaller study (n=34) (Miles, Gillespie, & Holditch-Davis, 2001). Baseline data from a longitudinal study with both men and women, disaggregated for women, was also available at the time of writing (Sherbourne, Forge, Kung, Orlando, & Tucker, 2003).

Overall morbidity, comorbidity and lifetime prevalence

Several studies have reported that a high proportion of women meet criteria for at least one clinical disorder, with figures ranging from 28-77% in contexts as diverse as Brazil (Tostes, Chalub, & Botega, 2004), France (Bungener, Marchand-Gonod, & Jouvent, 2000; Mellers et al., 1994), the UK (Catalan et al., 1996; Mellers et al., 1994) and the US (Brown & Rundell, 1993; Mellins, Erhardt, & Grant, 1997; Mellins, Ehrhardt, Rapkin, & Havens, 2000; Murphy, Koranyi, Crim, & Whited, 1999; Sherbourne et al., 2003; Taylor et al., 1996). Further, there is evidence of comorbidity in between 16 and 44% of HIV positive women (Bungener et al., 2000; Murphy et al., 1999; Taylor et al., 1996). Based on a large-scale study of HIV-infected US women, Sherbourne (2003) reported that 70% of those with a probable mood disorder did not have a comorbid drug or alcohol problem.

High lifetime histories of psychiatric disorders have also been reported amongst infected women (de Mello & Malbergier, 2006; Mellins et al., 1997). Mellins et al. (1997) reported that 88% of low income, African-American women in their sample had presented with at least one disorder at some point in their lives. For almost all of these women, the diagnosis was of a non-substance use disorder (78%), with depression the most common presentation at 58%. In a study conducted in Brazil, the lifetime rate of depression amongst HIV-infected women was 60% (de Mello et al., 2006).

Current mood disorders

With regard to women's current levels of functioning, the majority of research has investigated the prevalence of mood disorders and the rates of elevated levels of depressive symptoms. Most rates reported for major depression fall between 12 and 21% (Catalan et al., 1996; de Mello et al., 2006; Lipsitz et al., 1994; Mellins et al., 2000; Morrison et al., 2002; Myers & Durvasula, 1999; Taylor et al., 1996), with the highest rate reported by Brazilian women (de Mello et al., 2006). Outside of this range, Brown and Rundell (1993) report low rates of between 3 and 5% amongst largely asymptomatic, employed Air Force women, while rates of 23 and 39% were reported amongst European and African women in France (Bungener et al., 2000).

Although evidence is more limited, it appears that the rates for other mood disorders are lower, with rates for dysthymia reported at 1.7-13% (Brown et al., 1993; de Mello et al., 2006; Lipsitz et al., 1994; Mellins et al., 2000; Morrison et al., 2002), bipolar mood disorder at 13% (Mellins et al., 2000), adjustment disorder at 1.7-9% (Brown et al., 1993; de Mello et al., 2006; Lipsitz et al., 1994), and suicidal ideation at 12-13% (Brown et al., 1993; Sherr et al., 1997). One US study reported that 62% of infected women had attempted suicide (Swartz, Markowitz, & Sewell, 1998). However, nearly half of these women had also been incarcerated at some point and it is therefore likely that their experience is representative of a small minority of women living with HIV. The figure for contemplated suicidality amongst infected Brazilian women was much lower at 16% (de Mello et al., 2006).

Current mood symptoms

Perhaps unsurprisingly, the rates for self-reported symptoms of depression are higher than those for clinically diagnosed depression and mood disorders in general. Low rates were reported by Air Force women in the study referred to above (3-5%; Brown et al., 1993), a sample of women who self-enrolled at a HIV mental health clinic (6.6%; Reece, Basta, & Koers, 2004), and a convenience sample of low income women with symptomatic disease (6.8%; Van Servellen, Aguirre, Sarna, & Brecht, 2002). However, most other figures fall in the range of 30-66% (Bennetts et al., 1999; Breitbart et al., 1996; Catz, Gore-Felton, &

McClure, 2002; Ickovics et al., 2001; Johnson et al., 2001; Milan et al., 2005; Miles et al., 2001; Pergami et al., 1993; Richardson et al., 2001; Schrimshaw, 2002; Siegel, Karus, Raveis, & Hagen, 1998; Siegel et al., 2004; Simoni & Ng, 2000d; Simoni, Demas, Mason, Drossman, & Davis, 2000b; Tompkins et al., 1999; Tostes et al., 2004). Higher figures were reported only in two US studies with ethnic minority women (Catz et al., 2002), one of which included only Puerto Rican women (Siegel et al., 1998).

Rates of depressive symptoms based on either more conservative cut-off scores (employed to increase the clinical validity of the instrument) or the exclusion of somatic (as opposed to cognitive and affective) symptoms[18] still range from 29-60% (Bennetts et al., 1999; Catz et al., 2002; Milan et al., 2005; Schrimshaw, 2002; Siegel et al., 1998; Simoni et al., 2000b). Included in this supporting evidence is one study conducted in a developing country, namely Thailand (Bennetts et al., 1999). The only longitudinal study to examine depression in HIV-infected women (HERS - HIV Epidemiology Research Study) also reported relative stability in overall depressive symptoms and depression severity over a five-year period, with a slight trend toward improvement over time (Boland, Moore, & Schuman, 1999a; Ickovics et al., 2001; Milan et al., 2005).

Current anxiety disorders and symptoms

With regard to anxiety spectrum disorders, the evidence is more limited and much less consistent. However, high rates of posttraumatic stress disorder (PTSD) ranging from 18-50% have been reported in four different studies with low income, HIV-infected African American women (Kimerling et al., 1999; Martinez, Israelski, Walker, & Koopman, 2002; Mellins et al., 2000; Myers et al., 1999; Wood & Tobias, 2004). Only one study reported figures for each of panic disorder (9%) (Myers et al., 1999) and phobias (15%) (Mellins et al., 2000), while two studies reported figures of 5-8 and 29% for anxiety disorders in general (Bungener et al., 2000; Catalan et al., 1996). The high rate was reported by infected women in London, approximately one-third of whom had a history of IVDU (Catalan et al., 1996). However, this figure was not confirmed in a more recent (small) sample of London women (Bungener et al., 2000). Also, minority women and IVDU are

[18] All of these revisions have been undertaken in studies employing the CES-D (Centre for Epidemiologic Studies Depression Scale). The subject of the association between physical symptoms and somatic symptoms of depression will be discussed further in Chapters 3 (section 3.3.3.3) and 4 (section 4.2.1.2).

high-risk populations, suggesting that PTSD and other anxiety disorders may be unrelated to women's HIV status.

Rates of clinically elevated self-reported symptoms of anxiety vary considerably, with three studies reporting figures in the 3-6% range (Brown et al., 1993; Kaplan, Marks, & Mertens, 1997; Reece et al., 2004) and four studies from 37-75% (Pergami et al., 1993; Tostes et al., 2004; Van Servellen et al., 1998; Van Servellen et al., 2002). The highest rates of clinical anxiety were reported by women with symptomatic disease in the US. In addition, Brown et al. (1993) reported that levels of anxiety amongst their sample of mostly employed, asymptomatic women increased from 3 to 17% across a 14-month period. As noted earlier, the findings of this study have very limited generalisability to the large majority of women living with HIV at the present time.

Other current disorders

Rates of 22% for borderline personality disorder amongst a small sample of women (38) attending a US AIDS Centre have been reported (Taylor et al., 1996), as well as a 30-40% rate of hypoactive sexual desire disorder amongst infected women in the US Air Force (Brown et al., 1993). While rates for substance use disorders are available, they tend to be a function of the particular population sampled (for example IVDU) and are therefore not useful for more general consideration. As will be discussed in the next section, HIV-infected women who are also IVDU tend, unsurprisingly, to have higher overall levels of psychiatric morbidity.

2.2.1.2 Comparative levels of morbidity and distress

An important issue related to the prevalence of distress and disorder is how these levels of adjustment compare with those of other populations. Two different methodological approaches to this question were evident in the literature. One approach addressed the question empirically through the use of a control group designed to determine the levels of adjustment amongst similar non-infected women at the time of the study. The other approach employed existing norms for different population groups as a point of comparison.

Comparative norms

Of the 16 studies reviewed that compared findings with existing norms (several other studies made no comparison), fourteen reported that levels of morbidity or distress were higher than community norms. Two other studies found some symptoms elevated and others comparable to community norms. Only two studies reported that all findings were comparable with those for the general population (and therefore not elevated compared with women in general). The outcomes assessed included overall psychiatric morbidity (Mellers et al., 1994; Mellins et al., 1997; Milan et al., 2005; Moneyham, Sowell, Seals, & Demi, 2000; Murphy, Marelich, Dello Stritto, Swendeman, & Witkin, 2002; Siegel et al., 1998; Tostes et al., 2004), general distress (Hudson, Lee, Miramontes, & Portillo, 2001; Karus et al., 1999; Lipsitz et al., 1994; Mellins et al., 2000; Reece et al., 2004; Sharts-Hopko, Regan-Kubinski, Lincoln, & Heverly, 1996; Te Vaarwerk & Gaal, 2001), depression (Reece et al., 2004; Tostes et al., 2004) and PTSD (Martinez et al., 2002; Myers et al., 1999).

In addition to being elevated relative to community norms, levels of distress and morbidity in HIV-infected women were generally comparable to or greater than other medical populations but less than psychiatric inpatients, with the exception of IVDU. A study conducted in Brazil reported levels of depression consistent with medical inpatients (Tostes et al., 2004), while both this and another study conducted in France found levels of psychiatric morbidity higher than the general medical population (Mellers et al., 1994). Levels of (self-reported) distress amongst an ethnically diverse group of HIV-infected women in the US have been reported as one standard deviation above the mean for cancer patients (Karus et al., 1999).

Only one study that included almost no drug-using women in its sample reported levels of distress and depression consistent with psychiatric populations (Lipsitz et al., 1994; Reece et al., 2004; Sharts-Hopko et al., 1996; Te Vaarwerk et al., 2001). While it is unclear why levels were so high in this sample of African American women (Reece et al., 2004), it is clear that the finding goes against the trend emerging in the body of research as a whole.

Control group studies

The findings of studies that employ a non-infected control group to assess the impact of HIV status are more varied. Further, they are difficult to compare and integrate, with not all discrepancies readily explained by examination of sampling and other methodological differences. For the most commonly assessed outcome, self-reported symptoms of depression, four different studies with samples consisting mainly of low-income African American women, the minority of whom have advanced disease, have found that HIV status predicts higher levels of depression (Johnson et al., 2001; Jones, Beach, & Forehand, 2001; Jones, Beach, Forehand, & Family Health Project Research Group, 2003; Morrison et al., 2002; Tompkins et al., 1999). Clinician-rated depression has also been associated with HIV status (Lipsitz et al., 1994; Jones et al., 2003; Jones et al., 2001) and the association for both clinician-rated and self-reported depression has been shown to hold when assessing affective and cognitive depression only, thereby controlling for the potential overlap between disease and distress symptoms (Jones et al., 2001).

Richardson et al. (2001) failed to find an association between self-reported depressive symptoms and HIV status, however, as did three other studies, although one sampled women two to six months post-partum (Smith et al., 2001) while the other two included mainly IVDU (Lipsitz et al., 1994; Pergami et al., 1993). Further, one of the largest, most rigorous analyses undertaken with respect to this question reported that HIV status did not predict either incremental changes or the trajectory of women's depressive symptoms over a five-year period, even when controlling for the potential impact of self-reported somatic symptoms (Milan et al., 2005). One possible explanation for the absence of association in these studies is the relatively small number of symptomatic women that they include.

Other studies provide more consistent support for either the presence or absence of a link between HIV status and psychological adjustment, dependent on the outcome assessed. However, the limited number of studies addressing this question for certain outcomes, for example, suicidal ideation and psychosexual dysfunction, constrains confidence in the findings. The only available evidence with regard to (clinically-assessed) psychiatric morbidity (Catalan et al., 1996; Lipsitz et al., 1994), lifetime history of mental disorder (Gielen et al., 2005), PTSD and posttraumatic symptoms (Myers et al., 1999), anxiety

disorders (Morrison et al., 2002) and self-reported anxiety (Lipsitz et al., 1994; Morrison et al., 2002; Pergami et al., 1993; Smith et al., 2001) failed to demonstrate differences in mental health outcomes according to HIV status. Further, while a German study found higher levels of (self-reported) distress among infected women (Franke, Jager, Thomann, & Beyer, 1992), this finding was not confirmed in multivariate analyses conducted as part of an Italian study (Pergami et al., 1993). Women in both studies were mostly IVDU, however, only the latter included a control group (with similar proportions of IVDU and non-IVDU as in the comparison group). In contrast to the aforementioned outcomes, which suggest the absence of an association, levels of psychosexual dysfunction (Catalan et al., 1996) and suicidal ideation (Jones et al., 2003) have been reported as elevated amongst infected women relative to controls. As noted, the evidence is too limited from which to draw conclusions regarding women living with HIV more generally.

Of the available research, the clearest indication is that levels of depression and mood symptoms tended to be elevated amongst HIV-infected women compared with non-infected living in their communities. Evidence regarding other mental health implications is either unclear or inconsistent and may simply reflect the high levels of disturbance that occur amongst infected groups independent of HIV status.

2.2.2 HIV-related health predictors

Several studies examined the role of various HIV-related health factors as predictors of women's psychological adjustment. These included women's overall state of health (both perceived and objectively measured), the length of time since women's diagnoses, whether or not they are receiving antiretroviral therapy, and the severity of their disease.

2.2.2.1 Stage of disease

With regard to the impact of disease severity, several studies failed to find an association between severity of illness and women's quality of life (Bova, 2001; McDonnell, Gielen, Wu, O'Campo, & Faden, 2000). Also no links were found between this variable and general levels of distress (Te Vaarwerk et al., 2001), clinical wellbeing (Catalan et al., 1996), and (self-reported) levels of depressive and anxiety symptoms (Linn et al., 1994).

Other studies have, however, discerned a relationship. Lipsitz et al. (1994), Kaplan et al. (1997), Comer et al. (2000) and Sherbourne et al. (2003) in the US, Bennetts et al. (1999) in Thailand, and de Mello and Malbergier (2006) in Brazil reported that symptoms of depression, anxiety or suicidality and psychiatric disorder are associated with more advanced disease. However, Boland et al's (1999a) longitudinal study and Tostes et al. (2004) found that women with symptomatic disease reported the poorest quality of life and the highest levels of depression, respectively, compared with both asymptomatic women and women diagnosed with AIDS. Further, Reece et al. (2004) found the lowest levels of distress amongst AIDS-sick women compared with those in earlier stages of disease.

It is worth noting a difference in findings even amongst three developing country studies cited above, with Bennetts et al. (1999) reporting the greatest depression amongst post-partum women in Thailand with advanced disease. While de Mello et al. (2006) reported higher levels of depression amongst symptomatic versus asymptomatic Brazilian women, Tostes et al. (2004), also in Brazil, reported higher levels of depression amongst symptomatic compared with AIDS-sick women. The reasons for the difference in findings are unclear. However, the studies apply different approaches to stratification[19], thereby making comparison difficult.

2.2.2.2 Objective and subjective disease parameters

With the exception of time since diagnosis, other findings regarding health predictors are clearer to interpret. Research demonstrates convincingly that self-reported symptoms and other subjective disease parameters are the best predictors of infected women's mental health outcomes and not objective, laboratory markers (Jones et al., 2001; Rabkin, Ferrando, Lin, Sewell, & McElhiney, 2000). Thus while CD4 counts failed to predict levels of depressive symptoms (Boland et al., 1999a; Breitbart et al., 1996), higher levels of depressive and anxiety symptoms have been associated with poorer general health (Simoni et al., 2000b), poorer perceived health (Miles et al., 2001; Miles, Burchinal, Holditch-Davis, Wasilewski, & Christian, 1997), greater disruptions in physical wellbeing (Van Servellen et al., 2002; Van Servellen et al., 1998), greater activity limitations (Miles

[19] For example, de Mello et al. (2006) does not differentiate AIDS-sick from other symptomatic women and includes those with a history of qualifying symptoms as well as those with the symptomatic presentation at the time of the study, as is typically the case.

et al., 2001; Van Servellen et al., 1998), more pain (Breitbart et al., 1996), and greater number of HIV related symptoms (Breitbart et al., 1996; Linn et al., 1994; Miles et al., 2001; Miles et al., 1997; Moneyham et al., 2000; Richardson et al., 2001; Simoni et al., 2000b).

2.2.2.3 Time since diagnosis and use of HAART

With regard to time since diagnosis, three studies failed to find an association between levels of depression and time since diagnosis, including a five-year longitudinal study that controlled for the impact of self-reported somatic symptoms (Breitbart et al., 1996; Catz et al., 2002; Milan et al., 2005). However, other studies have reported that women with more recent diagnoses tend to have higher levels of depression (Boland et al., 1999a; Kaplan et al., 1997) as well as greater anxiety (Catz et al., 2002; Kaplan et al., 1997) and suicidal ideation (Gielen et al., 2005). The only study to systematically examine the impact of HAART reported that levels of depression did not differ amongst women in the pre- and post-HAART eras in the US (Siegel et al., 2004). However, women who had never used antiretrovirals or used them at the time of the study were less depressed than those that had discontinued use for some reason.

Taken together, the evidence indicated that women's self-reported symptoms and perceived health were most likely to be associated with psychological adjustment. Women who reported the poorest health and the largest number of symptoms also exhibited the higher levels of depression and other features of poor mental health. Evidence regarding other health-related factors such as women's disease severity and use of HAART remains unclear on the basis of the limited available research.

2.2.3 Non-health related predictors

2.2.3.1 Socio-demographic factors

The association between HIV-infected women's psychological adjustment and various socio-demographic factors has also been examined, with perhaps the most convincing relationship reported between low income and elevated levels of depression (Bennetts et

al., 1999; Kaplan et al., 1997; Richardson et al., 2001; Schrimshaw, 2002; Simoni et al., 2000d; Simoni et al., 2000b; Van Servellen et al., 2002). Kaplan et al. (1997) and Van Servellen et al. (2002) have found a relationship between poverty and anxiety, while Myers et al. (1999) reported an association with PTSD, and other studies with symptoms of psychiatric disorder and psychological distress in general (Mellins et al., 2000; Sherbourne et al., 2003). The finding does not always hold in more rigorous multivariate analyses, however (Bennetts et al., 1999; Sherbourne et al., 2003; Simoni et al., 2000d; Van Servellen et al., 2002).

Simoni et al. (2000b; 2000c) also found an association between high levels of depression and unemployment, and several studies have found low education to be a predictor of elevated levels of depression (Kaplan et al., 1997; Richardson et al., 2001; Schrimshaw, 2002; Simoni et al., 2000b; Simoni, Davis, Drossman, & Weinberg, 2000c; Van Servellen et al., 2002), anxiety (Kaplan et al., 1997; Van Servellen et al., 2002) and symptoms of PTSD (Myers et al., 1999).

With regard to ethnicity (and in some contexts ethnicity and income are highly correlated), the majority of (US) studies report poorer psychological wellbeing amongst infected minority groups, typically Latinas, Puerto Ricans or Hispanics compared with whites and sometimes African Americans as well. While some US studies reported higher levels of depression and psychological distress for Puerto Ricans, Latinas and Hispanics (Karus et al., 1999; Richardson et al., 2001; Schrimshaw, 2002; Siegel et al., 1998), others have found higher levels of depression and poorer quality of life amongst African Americans (Bova, 2001; Tompkins et al., 1999; Van Servellen et al., 2002). In the UK where minority status is often afforded to African immigrants, suicidal ideation has been found to be greater amongst ethnic minority women (Sherr et al., 1997). One contrasting finding, the meaning of which is unclear, is Reece et al.'s (2004) report that levels of stress symptomatic of hostility were higher among whites than blacks.

Findings regarding age and relationship status and their implications for mental health are generally less clear. Some research has found no association between relationship status and psychiatric morbidity in HIV-infected women. However, Kaplan et al. (1997) reported that women who had never been married exhibited higher levels of depression and anxiety

and Bennetts et al. (1999) reported that higher levels of depression were found amongst mothers of young children in Bangkok who did not have a partner. Examining relationships more generally, Sherbourne et al. (2003) found an association between psychiatric disorder and conflict with others as well as prior physical abuse. With regard to age, Mellers et al. (1994) reported that older age predicated higher levels of psychiatric morbidity amongst infected women in their London and Paris samples. However, this is not a finding that has been consistently reported in other studies (for example, Lipsitz et al., 1994; Myers et al., 1999; Sherbourne et al., 2003). In many cases, such variables are employed as controls or matching criteria in order to focus on other psychological factors more easily targeted in interventions.

2.2.3.2 Psychological factors

Several psychological factors have also been associated with infected women's mental health, most notably, substance use. As noted already (in section 2.2.1), HIV positive women who are also intravenous drug users are much more likely than other women to have levels of morbidity and distress consistent with psychiatric populations. Studies in the US, Italy, Germany, London and the UK have reported that intravenous drug use (Boland et al., 1999a; Lipsitz et al., 1994; Mellers et al., 1994), alcohol use (Pergami et al., 1993) and substance use in general (Richardson et al., 2001) were associated with elevated levels of depressive symptoms and clinical depression, psychological distress and psychiatric morbidity but not PTSD (Myers et al., 1999). Further, women who were both HIV positive and intravenous drug users have been found to exhibit greater levels of depression than men in general as well as non-infected women and non-IVDU infected women (Wisniewski et al., 2006). The association between substance use and depression and anxiety was not, however, evident in a sample of symptomatic women (Van Servellen et al., 1998). It may be that amongst women with more advanced disease, substance use is a less salient predictor of psychological wellbeing than when symptoms are minimal. Lipsitz (1994) also found that women receiving methadone treatment were more likely to have a diagnosis of major depression, further suggesting a link between substance use and poor mental health in infected women.

The association with past psychiatric history is less clear. Three studies have reported greater mental health problems in women with a history of substance use (Mellins et al., 1997), child sexual abuse (Gielen, McDonnell, Wu, Campo, & Faden, 2001) and psychiatric problems more generally (Pergami et al., 1993). However, Sherr et al. (1997) failed to find an association between previous hospital admissions and suicidal ideation, and Van Servellen et al. (1998) between psychiatric history and levels of depressive and anxiety symptoms in symptomatic women. The latter finding in particular is unexpected, but should perhaps be interpreted with caution given the small sample size (44) and the fact that neither a control group nor a randomised sampling approach was employed.

The impact of serious and daily stressors has also been examined. The research indicates that general life stress predicted poorer psychological adjustment in HIV-infected women (Boland et al., 1999a; Catalan et al., 1996; Catz et al., 2002; Lipsitz et al., 1994), including planning for an uncertain future associated with living with HIV (Murphy et al., 1999), serious traumas (Martinez et al., 2002; Mellins et al., 1997), and violence and abuse (Gielen et al., 2005; Jones et al., 2003; Milan et al., 2005; Richardson et al., 2001; Simoni et al., 2000d). The outcomes assessed were anxiety (Catz et al., 2002), depression (Boland et al., 1999a; Catz et al., 2002; Lipsitz et al., 1994; Richardson et al., 2001), adjustment in general (Mellins et al., 1997; Murphy et al., 1999) and, in the case of trauma, levels of PTSD (Martinez et al., 2002). Physical and verbal abuse (Jones et al., 2003) and intimate partner violence (Gielen et al., 2005) have been associated with suicidal ideation; intimate partner violence has been associated with anxiety (Gielen et al., 2005); and partner conflict (Milan et al., 2005) and violence (Gielen et al., 2005), domestic abuse (Richardson et al., 2001), physical, verbal and sexual abuse (Jones et al., 2003; Simoni et al., 2000d), and childhood physical and sexual abuse have been linked to higher levels of depression (Simoni et al., 2000d). Other factors associated with greater depression or general distress amongst infected women include lower levels of optimism (Van Servellen et al., 2002; Van Servellen et al., 1998), poorer self-esteem (Moneyham et al., 2000; Te Vaarwerk et al., 2001), an external locus of control (Pergami et al., 1993), low levels of self-efficacy (Sharts-Hopko et al., 1996), poorer quality of life (Moneyham et al., 2000), and low family cohesion (Moneyham et al., 2000).

Evidence regarding psychological factors therefore points most clearly to the role of substance use and non-HIV related stressors in women's lives, including levels of poverty. This further indicates the importance of untangling premorbid states and conditions from HIV-related outcomes, given that poverty and substance use are independently associated with poor mental health as being being risk factors for HIV infection.

2.3 THE NATURE OF SOCIAL SUPPORT AND ITS RELATIONSHIP TO PSYCHOLOGICAL ADJUSTMENT

As suggested earlier, social support is one of the central issues in this body of literature. There is considerable evidence demonstrating an association between multiple aspects of social support and psychological adjustment, both for the population in general and for PLWHA (DeLongis, Folkman, & Lazarus, 1988; Nott, Vedhara, & Power, 1995; Primomo, Yates, & Woods, 1990; Sarason & Sarason, 1994; Van Servellen et al., 2002). While the full extent of the theory around social support is beyond the scope of this chapter, the most important point to make is that social support has been implicated in the mediation of stressful life events, including dealing with illness (Heitzmann & Kaplan, 1988).

Secondly, (and important for both the present review and the research design to be discussed in Chapter 3) social support is a multi-dimensional concept. The dimensions typically considered in the social support literature are: structural properties of social support (such as size and relationship between network members, and the content and quality of relationships); types of social support available (such as instrumental and emotional support); and satisfaction with available support (Sarason et al., 1994). In some instances, a distinction is also made between support that is actually received or reported to be received, and that which the individual perceived to be available (Sarason et al., 1994).

An overview of the literature on social support and HIV is first provided, including evidence on the nature of women's experiences of social support and the associations between social support and other socio-demographic and health-related factors.

2.3.1 Network size

The size of the support networks of HIV-infected women is an area that has received limited attention. Average network size has been reported variously as 2 (Simoni et al., 1995), 7.4 (Comer, Henker, Kemeny, & Wyatt, 2000) and 13.46 (Hough, Magnan, Templin, & Gadelrab, 2005), with one study finding that larger support networks were predicted by higher levels of education (Comer et al., 2000). Further, Gray and Cason (2002) reported that network size ranged from 1 to 24 amongst their sample of 50% white women, more than half of whom were employed or homemakers. Other studies with Latina or African American women have found that 60% of women have network sizes of less than six (Gielen et al., 2001); 94% have someone to talk to, although 32% have only one person (Simoni et al., 1995); and 95% have at least one person to provide instrumental support and often emotional support, too (Ciambrone, 2002). In a small study of older, well educated Canadian women (half were over 40), all reported having someone who was helpful and supportive (Heath & Rodway, 1999). However, Gielen et al. (2001) found that one in ten women (12%), half of whom had a history of drug use, had no-one to confide in and a similar number (15%) had no financial support or a place to stay. Women with AIDS did not represent a sizeable proportion in any of the aforementioned studies.

2.3.2 Nature and quality of social support

2.3.2.1 Support from family members

In terms of the nature and composition of women's social support networks, findings regarding the role of family members are mixed. Siehnhold (1999) reported that HIV-infected women receive the least support from families (and the highest from medical personnel), while Hudson et al. (2001) similarly reported that friends rather than family were women's most frequent contacts. Thirteen to 24% of women never had social contact with family, while 29 to 41% felt that they did not spend enough time with close family members and only 30% felt that they spent adequate time with mothers and sisters (ibid). Sambamoorti, Crystal and Dermatis (1995) reported that women were also less likely than

men to receive support from a parent (as opposed to other kin or formal sources) and were 50% more likely than men to have unmet support needs in general.

In contrast, other studies conducted in London, France and the US have pointed to the family as a source of strength (Gray & Cason, 2002; Mellers et al., 1994; Owens, 2003). Reports have indicated that family, particularly immediate family, provide 22 to 84% of women's support, with only one cited study reporting a figure below 45% (Gillman & Newman, 1996; Hough et al., 2005; Weiner & Lorber, 1998). Research also showed that women without a history of IVDU and without a partner are much more likely to have supportive family networks (Ciambrone, 2002).

2.3.2.2 Support from partners, children and other network members

The findings regarding partner support are mixed. One study of mostly single, African American urban mothers reported that 5% had a husband as part of their support network (Hough et al., 2005), while 75% of women in another study who had a partner received support from them (Gillman et al., 1996). The latter sample consisted of mostly drug-using women, one in three of whom resided in a group home, prison or rehabilitation centre at the time of the research. Ciambrone (2002) reported that married women were most likely to identify their partner as a primary support person.

With regard to other network members, Weiner et al.'s (1998) findings indicated high levels of support from children (two in three women), while Gray and Cason (2002) reported that just over half of infected women listed children in their support networks. Figures in two other studies are considerably lower, at approximately one in three children (Gillman et al., 1996; Hough et al., 2005). However, two-thirds of women in one of these studies did not have children living with them (Gillman et al., 1996). Further, Hough et al's (2005) finding that children tended to represent women's closest support members (nearly half of those closest to them), while friends and family were more likely to be supporters with whom they had less close relationships, may be a more interesting one for understanding infected women's social support. Ciambrone (2002) has also reported that women with children and no history of drug use were more likely to identify children's role in their lives as important. It should be noted though that having children as support

for parents/carers is a complex issue that may have adverse implications for both adults and children, particularly in the longer-term[20] (Keigher, Zabler, Robinson, Fernandez, & Stevens, 2005; Klein et al., 2000).

Other findings regarding network composition show that: between 44 and 49% of women experience support from friends (Gillman et al., 1996; Simoni et al., 1995; Weiner et al., 1998); nearly half of women receive support from social workers (Simoni et al., 1995); and less than 15% from religious leaders or other spiritual influences (Hough et al., 2005; Simoni et al., 1995). Further, women's closest network members tended to be younger, lived closer and had more frequent telephone contacts and visits with them (Hough et al., 2005).

2.3.2.3 Quality of support received

While the composition of women's support networks is not uninteresting, some research suggests that perceived quality or adequacy of support is a more useful consideration in predicting women's psychological wellbeing (Sarason et al., 1994). While the above-mentioned studies as a whole indicate that family often (although not always) provide women with considerable support, several studies point to inadequacies in the manner in which this support is perceived. Weiner and Lorber (1998) reported that less than half of family members who were aware of women's HIV status were supportive, while Hough et al. (2005) reported that mothers with the highest proportion of family (other than children) as their intermediate supporters, experienced support as being less frequent, less available and less helpful.

Other US studies have reported that women perceived family as less supportive than friends (Serovich, Kimberly, Mosack, & Lewis, 2001); experience more unsupportive social interactions from family or partners than friends (Schrimshaw, 2003); and were less likely to perceive support from mothers and sisters as adequate compared with support from friends (Hudson et al., 2001). In contrast, research with white, Canadian women reported that family members were most helpful (Heath et al., 1999), while between one in three and just over half of French and British women described the quality of support

[20] For a discussion on HIV-infected women's disclosure to their children, see section 2.5.3 below.

received from family as satisfactory, good or very good (Bungener et al., 2000; Mellers et al., 1994). Both the latter studies, however, reported quality and satisfaction with support from friends as higher than that received from family.

Evidence regarding the nature and quality of HIV-infected women's social support is difficult to aggregate given its disparate nature. However, women's relationship histories with families and children in particular prior to their HIV infection appeared to play a role in determining the levels and quality of support that they received subsequent to diagnosis.

2.3.3 Factors associated with social support

2.3.3.1 HIV and other health related factors

Few studies explicitly address the question of whether social support differs in any respect according to either HIV status, severity of illness or time since women's positive diagnosis. Although a qualitative study has reported that HIV-infected women have a strong sense of perceived difference and often feel unworthy of engaging in the world of "seronegative people" (Ciambrone, 2002), two studies with quite different samples failed to find a difference in either the availability or satisfaction with social support according to HIV status. One was conducted with low-income, African American recent mothers, most of whom were asymptomatic (Smith et al., 2001), while the other was conducted ten years earlier with predominantly drug-using women in Italy (Pergami et al., 1993). In contrast, a (small pilot) study conducted in India reported that women received considerably less familial as well as socio-economic support after testing positive (Majumdar, 2004), while a study with low-income African American women found higher levels of social support than in the general population (Hudson et al., 2001). Clearly methodological differences prevent the comparison of these findings.

In terms of illness severity, one study reported that network size, distance from network members and frequency of telephone calls did not differ according to severity of illness (Hough et al., 2005). However, two other studies, both with high proportions of women with a history of drug use, found some differences. Schrimshaw (2003), in the US, reported

that women with symptomatic HIV have more unsupportive interactions[21] with family than asymptomatic women, while Catalan et al. (1996) reported that non-infected women in London had higher social integration than symptomatic women and received more guidance than both symptomatic and asymptomatic women.

Findings regarding time since diagnosis are also mixed. While Schrimshaw (2003) found no significant differences in unsupportive social interactions according to time since diagnosis, Ciambrone (2002) reported that women who had been diagnosed more than seven years previously were more likely to have unsupportive others. Gray and Cason (2002), in contrast, found that women tended to cultivate more support over time. It is likely significant that while the latter group of women were mainly white and either employed or homemakers, Ciambrone's (2002) sample consisted of a large number of former IVDU's who have been shown to be more likely to have unsupportive or difficult relationships. Further, women who did not have many friends prior to diagnosis were also likely to be more reluctant to seek out social interactions and therefore less likely to develop more substantial support networks over time (ibid).

2.3.3.2 Socio-demographic factors

Research also reported on the associations between social support and sex, age and ethnicity. Schrimshaw (2002) found higher levels of social conflict and lower levels of perceived available social support and social integration amongst HIV-infected women than HIV-infected gay men, as well as fewer unsupportive social interactions from spouses amongst older women (Schrimshaw, 2003). With regard to ethnicity, research has shown that African American women have greater perceived social support (Bova, 2001) and higher perceived social conflict than Latinas/Puerto Ricans and whites (Schrimshaw, 2002), somewhat contradictory findings, while also reporting that Puerto Ricans have the lowest social integration of all three groups (ibid). However, the role of ethnicity was not supported in multivariate analyses in Schrimshaw's study and is therefore a comparatively weak finding.

[21] Schrimshaw's (2003) research focuses on unsupportive social interactions based on the fact that negative and unsupportive interactions may exert a stronger influence on psychological adjustment than positive, supportive ones. Consequently the presence of more unsupportive interactions is not necessarily the same as the presence of fewer supportive interactions.

Research regarding sociodemographic and health-related factors associated with HIV-infected women's social support is generally mixed and therefore summary statements are of limited value. Several avenues remain for further investigation.

2.3.4 Social support as a predictor of psychological adjustment

2.3.4.1 The impact of social support on different types of adjustment

Different dimensions of social support have been variously related to psychiatric and psychological outcomes, indicating the presence and absence of a direct effect as well as a moderating role for social support. With regard to psychological distress in general, research has found that lower distress is associated with higher perceived cost of social support (Sharts-Hopko et al., 1996), greater social interactions and integration (Franke et al., 1992; Hudson et al., 2001), greater perceived emotional and instrumental support (Franke et al., 1992; Gielen et al., 2001; Hudson et al., 2001), and greater need for and satisfaction with social support (Simoni et al., 2000b). Further, smaller network size has been associated with poorer quality of life and mental health (Gielen et al., 2001). However, a study conducted in Italy with predominantly IVDU, failed to find an association between social support and psychiatric distress (Pergami et al., 1993).

In terms of other outcome measures, poorer perceived social support has been associated with higher rates of panic disorder (Myers et al., 1999) and greater network size with less stress (Serovich et al., 2001). Findings on depression and anxiety are varied. There is evidence to indicate that greater network size (Serovich et al., 2001), greater *perceived* network size (Catz et al., 2002), and higher levels of social support (Van Servellen et al., 1998) predict less anxiety. However, there is also evidence that fails to demonstrate an association between levels of support and anxiety in infected women (Van Servellen et al., 2002). Similarly, with respect to depression, while some studies do not support an association between either actual or perceived levels of support and depression (Schrimshaw, 2002; Van Servellen et al., 1998), others indicate that lower levels of depression are predicted by greater perceived network size (Catz et al., 2002), higher levels of perceived social integration and lower levels of social conflict (Schrimshaw, 2002), higher levels of support (Van Servellen et al., 1998), including from family (Richardson et

al., 2001), greater quality of support (Breitbart et al., 1996), and greater satisfaction with support (Simoni et al., 2000b).

Further, while Linn et al. (1994) failed to find a main effect for social support on depression, they reported that women with larger social networks had a high sense of coherence which was in turn associated with lower levels of depression. Bova (2001) and Mellins et al. (2000) also argued for a more complex relationship, the former showing that appraisal of illness mediated the effect of social support on women's psychological adjustment, while the latter reported that social support only moderated levels of distress amongst women with low (as opposed to high) levels of general stress. It may be that at the high levels of stress (experienced by a significant proportion of women living with HIV), the impact of support is not substantial enough to serve as a protective factor for psychological wellbeing.

One methodological difficulty that must be considered with all of the above findings is the fact that psychiatric morbidity and distress can influence perceptions of social support. For example, women who are more depressed are likely to perceive lower levels of support while those with better psychological adjustment are likely to perceive higher levels of support. Consequently, poorly adjusted women's self-reports can be a function of both their objective and subjective experience of their support system, and even an interaction between them. This is apparent in a number of the abovementioned findings. For example, poorer perceived social support has been associated with higher rates of panic disorder (Myers et al., 1999), while lower distress is associated with greater perceived emotional and instrumental support (Franke et al., 1992; Gielen et al., 2001; Hudson et al., 2001), and greater satisfaction with social support (Simoni et al., 2000b).

2.3.4.2 The impact of specific supportive relationships

A few studies examine the impact of support from different relationship sources rather than global support as a predictor of HIV-infected women's adjustment. This research demonstrates that more perceived support from family was associated with less depression and stress (Serovich et al., 2001). More support from family and friends was associated with less recent loneliness (ibid) and lower rates of PTSD (Martinez et al., 2002), and more

support from family with less loneliness in the previous year (Serovich et al., 2001). Further, Schrimshaw (2003) reported that unsupportive social interactions with friends, family and partners were associated with higher levels of depression. However, interaction effects were evident. Thus while high levels of unsupportive interactions with family directly predicted high levels of depression, high depression was predicted by high levels of unsupportive interactions from either or both partners and friends, and low depression by the absence of unsupportive interactions with either source.

With regard to support from children, Klein et al. (2000) reported that while more social and emotional support from neighbours and friends predicted decreased psychological distress in HIV-infected (and noninfected) women, there was some evidence that higher levels of emotional support from children were associated with greater psychological distress. This finding may be indicative of the fact that supportive children tend to act as substitutes in the absence of more adaptive sources of adult support, but that children are unable to effectively meet the emotional needs of their ill parents/caregivers (ibid). Alternatively, mothers may experience their children's support as reflecting the failure of their caregiving role which in turn is associated with poorer psychological wellbeing. This interpretation is supported by the fact that higher levels of parenting support have been associated with reduced perceptions of parenting self-competence in HIV-infected women in contrast to noninfected women (Dorsey, Klein, & Forehand, 1999). Moreover, many infected mothers are either reluctant to seek assistance, or resist seeking assistance (Ciambrone, 2003; Thorne, 1990) since they equate soliciting support with being a failure as a caregiver (Freeman, 2004).

While evidence indicates that social support plays some role in the psychological adjustment of HIV-infected women, findings regarding the nature of this role are fairly mixed. They do not indicate a clear simple link between social support and women's mental health in the context of HIV/AIDS.

2.4 THE NATURE OF COPING AND ITS RELATIONSHIP TO PSYCHOLOGICAL ADJUSTMENT

Coping, like social support, is a multifaceted concept. It will not be explored in any detail here (see Jenkins & Coons, 1996 for further discussion). However, two points bear mentioning. First, coping should not be confounded with outcome; coping refers to the purpose a strategy serves while outcome is the effect of that strategy. The coping process (as defined by Lazarus and Folkman (1984, p. 141)) is therefore "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person."

Since strategy and outcome are not necessarily linked, this approach rejects the idea of hierarchies of coping strategies, for example, the idea that denial is inevitably an inferior strategy with negative outcomes. However, it is useful to conceptualise coping in different types, an approach taken in much of the literature. One of the most common distinctions made is between emotion-focused coping aimed at reducing or managing the emotional distress associated with a given situation (for example, avoidance, minimisation, distancing and positive reframing) as opposed to problem-focused coping (for example, planning and seeking support) that aims to problem solve or alter the source of the stress (Carver, Scheier, & Weintraub, 1989). While emotion-focused coping is often found to increase psychological distress, problem-focused coping typically reduces distress (Folkman, Chesney, Pollack, & Phillips, 1992). The second important point is that there is clear evidence that coping strategies have a bearing on psychosocial and psychological adjustment, in the population in general, amongst the medically ill (Cohen & Lazarus, 1979; Lazarus & Folkman, 1984) and amongst PLWHA more specifically (Namir, Woolcott, Fawzy, & Alambaugh, 1987).

Some preliminary evidence on coping will be reviewed before examining coping as a predictor of psychological adjustment.

2.4.1 Type and frequency of coping strategies

Four published quantitative studies report on the type and relative frequency of coping strategies employed by HIV-infected women. However, the diversity of the samples considerably limits the usefulness of comparisons.

Bennetts et al. (1999) reported that venting, followed by denial and active coping were the most frequently used strategies amongst young, low income Bangkok women, most of whom were asymptomatic. However, confrontive coping was observed most often ins tudies of African American mothers of HIV positive children who were perhaps less able to use denial and avoidance due to the need to provide appropriate health care for their infected children (Rose et al., 1996a). Reports of denial and avoidance as well as self-blame and substance use were also relatively low amongst another sample of African American women, 30% of whom were sex workers (Kaplan et al., 1997). Three quarters of these women used prayer and attempts to discover meaning in their lives as a means of coping, and more than half engaged in wishful thinking (ibid). Evaluating quite different strategies in a sample of military women, most of whom were white, employed and economically secure, Nannis, Patterson and Semple (1997) reported that 43% of these women adopted a fighting spirit, while a third also displayed stoicism. A helpless/hopeless approach to coping was not employed by any woman unless in conjunction with another (more adaptive) strategy.

Several qualitative studies have also examined coping strategies, with religion or spirituality[22] emerging as one of the strategies that is reported amongst ethnically diverse women in the US (Mayers, Naples, & Nilsen, 2005), African Americans (Marcenko & Samost, 1999), (predominantly) white women in the US (Ciambrone, 2003; Gray et al., 2002), and Africans residing in London (Doyal & Anderson, 2005). These studies

[22] There is a tendency to conflate religion and spirituality and to assume that they are related to attendance at a place of worship. However, others have differentiated between coping that involves religion/religiosity/ religious wellbeing, spirituality and existential wellbeing (Coleman, 2003; Coleman & Holzemer, 1999; McCormick, Holder, Wetsel, & Cawthon, 2001). While religiosity typically includes worship as part of organised religion, existential wellbeing refers to an individual's sense of meaning and purpose in life. Spiritual wellbeing has been defined (in the Spiritual wellbeing scale) as a broader concept that encompasses both religious and existential wellbeing (Dalmida, 2006; Ellison, 1983). While research with HIV-infected women is not yet that sophisticated, the limited available research with PLWHA in general suggests that existential wellbeing is a better predictor of psychological wellbeing than religious wellbeing and that the differentiation of these concepts is therefore useful (Coleman et al., 1999; Tuck, McCain, & Elswick, 2001).

variously reported seeking or strengthening religious ties (Ciambrone, 2003; Mayers et al., 2005) and the fact that prayer and faith were central in women's lives, sometimes accounting for a turning point towards greater hope (Marcenko et al., 1999). Gray and Cason (2002) also reported higher levels of spiritual perspective amongst predominantly white, employed infected women than low income, infected women. Further, women who achieved what Gray and Cason termed "mastery over stress", perceived themselves as having high levels of spirituality.

Other strategies that infected women have described include: going public with their HIV status and joining support groups which enabled them to educate themselves about their illness and/or teach and share their experiences with others (Ciambrone, 2003; Mayers et al., 2005); adopting a positive outlook (Marcenko et al., 1999) and lifestyle, including engaging in better self-care (Ciambrone, 2003); and assigning a positive diagnosis meaning by interpreting the event as necessary or important (Mayers et al., 2005). Other women have reframed the situation as one in which they received special protection despite becoming infected, or universalised their experience by placing it in the context of other chronic illnesses and life stressors in general, particularly for those who live in endemic poverty (ibid). Denial (Ciambrone, 2003; Hackl et al., 1997), avoidance (Ciambrone, 2003), concealment, isolation and crying have also been reported (Hackl et al., 1997). These strategies serve to protect women from a diagnosis they cannot (yet) accept, protect them from feared rejection and stigmatisation, and, when necessary, release emotions that they can no longer contain.

2.4.2 Factors associated with coping

2.4.2.1 HIV and other health related factors

Several studies have examined associations between coping strategies and HIV status, illness severity, time since diagnosis and the use of HAART, with only one reporting the absence of a significant association (Ball, Tannenbaum, Armistead, Maguen, & Family Health Project Research Group, 2002). In a sample of low income, African American mothers, they failed to find any differences in coping styles according to either HIV status or stage of illness, concluding that infected women's health may not have been a

sufficiently significant concern relative to other life stressors given that most were asymptomatic. However, the study did report that while problem-focused coping was associated with poorer functioning in asymptomatic women, the inverse applied to symptomatic women (ibid).

Other studies have reported that HIV-infected women use higher levels of avoidant coping (Smith et al., 2001), mental disengagement (Catalan et al., 1996), support coping (including seeking instrumental support) (Catalan et al., 1996; Smith et al., 2001) and prayer (Biggar, Forehand, Devine, Brody, & Armistead, 1999). They were also more likely to be religious in general (Ciambrone, 2003). No differences were reported in church attendance (Biggar et al., 1999) or the use of active coping (Smith et al., 2001). Religion appeared to offer women consolation, emotional support and a sense of belonging (Ciambrone, 2003). However, despite the use of prayer, infected women were cautious in their beliefs regarding the importance of prayer as a coping strategy (Biggar et al., 1999).

Research has also shown that greater religiosity and healthier lifestyles are predicted by longer time since diagnosis, while avoidant coping is more common in women more recently diagnosed (Ciambrone, 2003). Further, while Hough et al. (2003) reported that greater severity of illness was associated with passive, tension-reducing coping strategies such as crying, excessive eating and sleeping, and daydreaming, Moneyham et al. (1998) reported that active coping is most effective when symptoms are visible and avoidant coping when symptoms are minimal and uncertainty high.

One recent study examined the relationship between coping strategies and women's access to HAART. Comparing women in the pre-HAART and HAART eras, Siegel and Schrimshaw (2005) found that women in the post-HAART era employed more emotion-focused and avoidant coping, including refusing to believe that it happened, keeping feelings to themselves and believing that they brought the problem on themselves. While unexpected in some respects, Siegel and Schrimshaw account for this finding by noting that women in this period also experienced more health-related stressors and stress related to discrimination and disclosure. Such situations that are not under one's direct control have been associated with the use of emotion-focused coping.

2.4.2.2 Socio-demographic factors

Associations between coping and a range of socio-demographic have been examined. Sowell et al. (2000) reported the highest use of spiritual resources amongst low and high, as opposed to middle, income women, while Simoni et al. (2000d) reported less avoidant coping amongst HIV-infected women with more education, higher income and current employment. Less avoidance has also been associated with having a partner, while establishing a positive lifestyle (including good eating, exercising and abstaining from drug use) was more likely amongst women without a partner (Ciambrone, 2003). With regard to ethnicity, two separate studies have reported that African Americans had more positive appraisals of living with HIV than whites and Latinas (Bova, 2001) and were less likely than whites to engage in self-blame but more likely to keep feelings to themselves (Kaplan et al., 1997).

2.4.2.3 Other non-health related factors

On a more psychological level, women with greater social support have been reported to be more likely to employ active meaning-making strategies (Hough et al., 2005) or to display a fighting spirit (Nannis, Patterson, & Semple, 1997), while less social support was associated with stoicism or a helpless/hopeless approach to coping (ibid). In terms of other (comparatively) adaptive strategies, higher perceived self-efficacy and shorter duration of an HIV-infected child's illness have been associated with greater use of problem focused coping (Sharts-Hopko et al., 1996), and greater disclosure with adaptive, as opposed to avoidant, coping in general (Simoni et al., 2000b). Further, passive and emotive coping and behavioural and emotional disengagement were associated with substance use (Rose & Clark-Alexander, 1996b) and higher perceived levels of stress respectively (Koopman et al., 2000).

2.4.3 Coping as a predictor of psychological adjustment

In terms of the relationship between coping and psychological outcomes, the link with depression, anxiety, quality of life, optimism, and distress, adjustment and morbidity in general have all been examined.

With regard to depression, studies have found lower levels of depression amongst HIV-infected African American women with higher levels of self-esteem and mastery (Neff, Amodei, Valescu, & Pomeroy, 2003) and a greater sense of meaning and purpose (Linn et al., 1994). Other studies have reported less depression amongst women more likely to use adaptive coping (Simoni et al., 2000b; Simoni et al., 2000d) and less likely to use avoidant coping (Catz et al., 2002; Simoni et al., 2000b; Simoni et al., 2000d). Greater use of problem solving (Commerford, Gular, Orr, Reznikoff, & O'Dowd, 1994; Neff et al., 2003) and greater emotion-focused coping have also been associated with less depression (Ball et al., 2002; Commerford et al., 1994).

Woods et al. (1999) reported an association between religious coping and less depression amongst predominantly low income, African American or Latina women. However, Biggar et al. (1999) failed to find a link between religious activity and depression amongst African Americans, instead associating religiosity with optimism. This suggests that prayer may have been viewed as providing a more positive sense of the future rather than alleviating distress. Also in contrast to the above, Bennetts et al. (1999) found venting was associated with high (rather than low) depression amongst young, low income mothers in Bangkok.

With regard to other outcomes, greater use of religiosity predicted lower levels of anxiety (Woods, Antoni, Ironson, & Kling, 1999) and emotional distress (Sowell et al., 2000) although the relationship with quality of life in general was less significant (ibid; Weaver et al., 2004). The use of emotion-focused coping (such as self-blaming denial, emotional expression and wish-fulfilment fantasy) was associated with greater anxiety (Commerford et al., 1994), but better quality of life (Rose et al., 1996a) and less general psychological distress (Ball et al., 2002). Of three studies, all with similar samples, one found an association between increased use of avoidant coping and decreased distress (Simoni et al., 2000b), and two failed to link avoidance with anxiety (Catz et al., 2002) or emotional distress (Moneyham et al., 1998). Denial, however, has been associated with poorer quality of life in infected women (Weaver et al., 2004). A large-scale study conducted in the US demonstrated the predictive power of avoidant coping on psychiatric disorder in a multivariate analysis (Sherbourne et al., 2003).

Of the more (typically) adaptive strategies, active coping, including seeking social support and actively managing one's illness, has been associated with lower levels of general distress (Bunting, 2001; Moneyham et al., 1998; Simoni et al., 2000b) and anxiety (Catz et al., 2002), while acceptance, positive reframing and active meaning making have been associated with decreased emotional distress (Hough et al., 2005) and improved quality of life (Weaver et al., 2004) or wellbeing (Bunting, 2001). Further, adopting a fighting spirit, as opposed to being hopeless/helpless, was associated with reduced distress amongst predominantly white, infected women affiliated with the military (Nannis et al., 1997).

Other findings with respect to coping and adjustment are that appraisal of illness (as per Lazarus and Folkman's (1984) model) is the primary determinant of individual variation in distress (Moneyham et al., 1997). In addition, Catalan et al. (1996) reported that coping strategies do not contribute to psychiatric morbidity, as opposed to levels of distress as assessed in most studies. Some studies address the nature of the relationship between coping and psychological adjustment, including the relative impact of coping. Neff et al. (2003), for one, reported that women's individual resources, in particular, self-esteem and mastery, had a more consistent impact on psychological adjustment than coping styles. Further, one of the larger-scale studies on coping in HIV-infected women reported that active coping mediated the relationship between HIV symptoms and emotional distress (Moneyham et al., 1998). Other studies have found that appraisal of illness mediated the relationship between social support and adjustment (Bova, 2001), satisfaction with social support mediated the relationship between adaptive coping and greater psychological wellbeing (Simoni et al., 2000b), and active coping and self-efficacy mediated the relationship between depression and religious coping (Woods et al., 1999).

As with social support, the literature on coping suggests its importance for the psychological adjustment of HIV-infected women, but without indicating a clear body of findings. However, avoidance, religion and active coping (including seeking social support) emerged in several studies as playing an important role in women's attempts to cope with a positive diagnosis. This in turn suggests their contribution to women's mental health outcomes.

2.5 HIV-RELATED STIGMA AND DISCLOSURE

2.5.1 Reasons for disclosure

Among the many psychosocial risks for HIV-infected mothers are AIDS-related stigma and decisions regarding disclosure. Disclosure may facilitate access to social support and health benefits, reduce risks of stigma and infecting significant others, and provide an opportunity to openly discuss custody planning (Kahn, 2005). However, the fear of stigma, rejection, relationship changes, social isolation, violence, and discrimination against the individual and other family members, remain significant barriers (Kirshenbaum & Nevid, 2002; Letteney & LaPorte, 2004; Murphy, Marelich, & Hoffman, 2002; Shaffer, Jones, Kotchick, & Forehand, 2001). Most women and mothers with HIV/AIDS report carefully weighing the risks and benefits of disclosing their status to others (DeMatteo, Wells, Goldie, & King, 2002; Moneyham et al., 1996) and continue to do so despite having had positive experiences and generally becoming more open over time (Moneyham et al., 1996; Winstead et al., 2002).

In a study with predominantly asymptomatic, African American mothers, Winstead et al. (2002) reported that fear of rejection and stigma (68%) followed by concerns about privacy (48%) were the most frequently cited reasons for non-disclosure, while the need for emotional support (60%) was the most common reason for deciding to disclose. Similarly, Simoni et al. (1995) found that self-focused reasons typically motivated disclosures to parents and friends although not to partners of whom the fear of rejection and desire to avoid rejection was more likely to drive non-disclosure.

Non-disclosure to parents was, however, associated with the desire to protect the person from worrying, feeling ashamed or due to the perceived ignorance of the individuals concerning HIV/AIDS (ibid). Women in Moneyham et al.'s (1996) study also reported confidentiality and discrimination by someone in a position of relative power (e.g. employer) as major concerns. In addition, while women found disclosure to children particularly difficult, they feared non-disclosure might result in children hearing about their mother's status from other sources (ibid).

2.5.2 Rates of disclosure

2.5.2.1 Overall rates of disclosure

Various rates of disclosure have been reported, both overall and for different types of relationships. Studies with predominantly low-income, ethnic minority women in both the US and London tend to report high rates of disclosure. In the US, Tompkins et al. (1999) and Comer et al. (2000) reported that infected women had disclosed to most of their social network, with 35% of women in Comer's study disclosing to all network members. Similarly, Simoni et al. (2000b), also in the US, and Sherr et al. (1997), in London, reported that 90 and 98% of women had disclosed to at least one person respectively. Amongst women most of whom had a history of drug-use, French women had disclosed to at least one friend or family member (Mellers et al., 1994) while 72% of US women had disclosed to ten or more people (Gillman et al., 1996). Rates were much lower for a group of London women with a similar drug use history, 25% of whom had not disclosed to anyone (Mellers et al., 1994). In a different London sample, 20% of women had not disclosed to anyone outside of their health care team (Doyal et al., 2005).

While the majority of these studies report high levels of disclosure amongst HIV-infected women, it should also be noted that disclosure may be a required precursor to treatment access in some settings, or at least something that women are persuaded in the strongest terms to do with at least one person in their immediate environment. In addition, several studies have found that women disclose to small numbers of individuals, particularly when looking beyond health care providers. For example, Sherr et al. (1997) reported that one in five London women in their clinic sample had only disclosed to one person, while Bennetts et al. (1999) reported that more than half of their sample of women from Bangkok had only disclosed to their partner.

2.5.2.2 Disclosure to particular individuals

Figures for disclosure to mothers and sisters across several studies range from 16-85% for mothers and 40-80% for sisters (Bungener et al., 2000; Kalichman, DiMarco, Austin, Luke, & Difonzo, 2003a; Simoni et al., 1995; Simoni et al., 2000b). A wide range has also

been reported for disclosure to partners, friends, brothers and fathers (Bungener et al., 2000; Doyal et al., 2005; Kalichman et al., 2003a; Simoni, Demas, Mason, Drossman, & Davis, 2000a; Simoni et al., 1995; Sowell et al., 1997). A study among rural women in the US reported that the highest rate of disclosure was to health care providers at 90% (Sowell et al., 1997). This may be indicative of the level of perceived and actual stigma in a rural community, but could equally reflect the requirement of health care providers to disclose as mentioned above.

With regard to disclosure of maternal HIV status to children, studies also reported a wide range of rates indicating that between 28 and 68% of mothers disclosed their HIV status to at least one of their children (Armistead, Morse, Forehand, Morse, & Clark, 1999; Armistead, Tannenbaum, Forehand, Morse, & Morse, 2001; Kirshenbaum et al., 2002; Murphy, Steers, & Dello Stritto, 2001; Murphy, Roberts, & Hoffman, 2002; Simoni et al., 2000c; Tompkins et al., 1999; Winstead et al., 2002). Of course in some studies, low rates could be explained by the fact that women in the sample had particularly young children, such as in Winstead et al. (2002) where half of the women who had not disclosed had children younger than the age of three years. In addition, studies have variously reported that 51% of children had been told something about their mothers' illness, although only 13% knew that their mother might die of AIDS (Murphy et al., 2001); and that 3% had not received any information regarding their mother's ill health (Kirshenbaum et al., 2002). It has also been reported in two separate studies that the majority of mothers asked the child to keep their status a secret for fear of repercussions such as stigma and ostracism for both themselves and their child (ibid; Murphy et al., 2002). In one of these studies, one in four mothers identified a "safe person" for the child to discuss the mother's HIV status with (Murphy et al., 2002).

2.5.3 Reactions to and consequences of disclosure

There is some evidence to suggest that women have legitimate concerns regarding the disclosure of their HIV status, particularly to partners in areas where levels of intimate partner violence are high (UNAIDS/UNFPA/UNIFEM, 2005). Violence or being thrown out of one's home, which can in turn negatively impact on mental health, may therefore be understandable concerns. Further, a related point is that women who are more depressed or

have higher levels of distress in general also tend to perceive higher levels of threat associated with disclosure, even over and above that which is objectively required.

However, despite women's considerable concerns regarding the response to disclosure, at least two studies that report on general reactions indicated that women were met with mostly favourable responses (Ciambrone, 2002; Simoni et al., 1995). Some women did have confirmatory experiences of rejection by parents (Ciambrone, 2003), with a study conducted in London and Paris reporting that as many as one in five experienced a negative reaction from one or both parents (Mellers et al., 1994). However, overall, parents were supportive, with mothers especially likely to become protective following a daughter's disclosure (Ciambrone, 2002; Kalichman et al., 2003a; Winstead et al., 2002). One study reported that more than half of families (62%) and friends (55%) became closer following disclosure compared with only one in three partners (30%) (Winstead et al., 2002). Similarly, Simoni et al. (1995) found that partners were the most likely to become angry and rejecting, and Mellers et al. (1994) reported that negative reactions from friends were unusual.

Women in at least three studies found that children tended to be loving and accepting and offer support to their mothers following disclosure and that disclosure increased the closeness in the relationship (Ciambrone, 2002; Tompkins et al., 1999; Winstead et al., 2002). Further, children have been reported to be protective, to remind mothers of their medication, and to want more education about HIV/AIDS (Marcenko et al., 1999; Winstead et al., 2002). More adverse reactions include fear of the unknown, separation and death (ibid), and the finding that one in four children reacted with anger, disinterest, lack of sympathy and even cruelty (Ciambrone, 2002; Winstead et al., 2002). It should be noted, however, that many of the mothers in the latter study had a history of significant drug use and that it may not be possible to attribute the child's reactions to disclosure in the narrow sense as opposed to the nature of the relationship with their mother in general which may have been troubled.

Mothers often perceive the consequences of disclosure as considerably more negative than their children (Murphy et al., 2002; Shaffer et al., 2001), perhaps resulting in the withholding of information to the child's detriment. Shaffer et al. (2001) found that while

children reported an increase in knowledge about HIV, and no increase in adjustment problems or deterioration in relationship quality with their mothers, mothers perceived an increase in children's externalising problems. However, three separate analyses failed to find a relationship between child adjustment and mother's disclosure of HIV status (Armistead et al., 2001; Bauman, Camacho, Silver, Hudis, & Draimin, 2002; Forehand et al., 1998).

2.5.4 Factors associated with disclosure

Several factors have been associated with the nature and level of women's HIV-related disclosures. However, given the predominance of cross-sectional studies, causal relationships, and in many cases even the direction of effect, have not been definitively established.

2.5.4.1 HIV and other health related factors

With respect to health-related factors, findings from studies with predominantly African American women are inconsistent. While Gillman et al. (1996) reported that fewer disclosures were associated with more recent diagnoses, Murphy et al. (1999) found no relationship between disclosure and time since diagnosis. Further, while some studies have found that disclosure to children and adults is not influenced by severity of illness (Comer et al., 2000; Murphy et al., 1999; Shaffer et al., 2001; Simoni et al., 2000c), others point to a range of different relationships. For example, there is evidence linking illness severity to greater disclosure in general (Armistead et al., 1999; Comer et al., 2000) and more detailed disclosures to children (Kirshenbaum et al., 2002). However, there is also evidence suggesting that women with fewer symptoms are more likely to disclose to partners (Armistead et al., 1999).

2.5.4.2 Non-health related factors

Non-health related factors may also play a role in disclosure. Focus group research in the US indicated that women's disclosures were influenced by their level of acceptance of their diagnosis and their anticipated reactions drawn from other people's experiences

(Marcenko et al., 1999). Similarly, Ciambrone (2003) reported that women who feared rejection tended to wait longer to disclose, and that women who had been rejected by an intimate partner were likely to generalise an expectation of rejection to others. Clark et al. (2003) found that disclosure moderated the relationship between stigma and psychological adjustment, however, the finding only held for high levels of disclosure. Research has also shown that women with lower levels of perceived stress (Murphy et al., 1999) and higher levels of social support (Murphy et al., 2001) are more likely to disclose their status to people in general and to children respectively, while having a psychiatric history has been associated with more detailed disclosures by mothers to their children (Kirshenbaum et al., 2002).

2.5.4.3 Socio-demographic factors

In terms of socio-demographic factors, several studies have found an association between ethnicity and disclosure. Researchers in both Europe and the US have associated ethnic minority status with disclosing to fewer individuals (Comer et al., 2000; Sherr et al., 1997), with the exception of Simoni et al. (1995) who reported that Spanish speakers disclosed to more people than English speakers. One UK study also reported that ethnic minority women limited disclosure largely to family members (Sherr et al., 1997). This finding might be explained by the fact that disclosure was more likely to be perceived as placing a significant burden on important others in more collectivist cultures (Comer et al., 2000). This is consistent with Bungener et al.'s (2000) finding that European French women were more likely to disclose to family members and to friends than (minority) African French women (69 vs. 38% and 70 vs. 38%, respectively), with significant differences noted across disclosures to mothers and sisters in particular.

Research also indicated that friends and sisters were more likely to be disclosed to than any other category across both men and women (Kalichman et al., 2003a), women were more likely than men to disclose to mothers (ibid), rates were higher for immediate than extended family (Simoni et al., 1995), and women were more likely to disclose to family and close friends than acquaintances and employers (Sowell et al., 1997). Comer et al. (2000) found that older, more educated women disclosed more frequently, while Simoni et al. (1995) reported that younger age was associated with greater disclosures. It is unclear

how to account for the differences in the latter two findings since the samples are in many ways similar (despite the five year-period in between publication).

A clearer set of findings indicates that mothers' disclosures regarding their health condition become more detailed as children get older (Armistead et al., 2001; Kirshenbaum et al., 2002; Rotheram-Borus, Draimin, Reid, & Murphy, 1997; Simoni et al., 2000c), and that mothers are more likely to disclose to older children and to girls (Armistead et al., 2001; Shaffer et al., 2001). In Murphy et al. (2002), the average age of children to whom mothers had disclosed was nearly ten years old, while the children in Kirshenbaum and Nevid's (2002) study were significantly younger, at seven years of age. As a whole this suggests that women do not disclose their status to children not yet of school-going age.

Overall, the literature clearly indicates the centrality of disclosure for HIV-infected women. It also suggests that the decision to disclose is often a complex one influenced by a range of factors, with women sometimes predicting more negative consequences than they actually experience.

2.6 MOTHERING AND OTHER CARE ROLES OF HIV-INFECTED WOMEN

Mothering and parenting practices are important themes that emerge in psychosocial research on HIV-infected women, and therefore deserve separate consideration.

2.6.1 The complexities of the maternal identity

To begin with, one of the findings to emerge from a metasynthesis of qualitative studies focusing on mothering in HIV-infected women is that being a mother is central to their lives (Sandelowski et al., 2003). Children were their reason to live, to get off drugs, to become involved in AIDS causes and to take care of themselves, as well as being a source of self-esteem, strength, hope and sense of wellbeing (Sandelowski et al., 2003; Van Loon, 2000). Children also moderated women's existential anxiety and sense of isolation by forcing them to maintain contact with the outside world in order to care adequately for their children (Mayers et al., 2005). This was evident in the fact (as noted in Chapter 1)

that many women prioritised the needs of their children over and above their own (Bunting, 2001; Ciambrone, 2003; De Marco, Miller, Patsdaughter, Grindel, & Chisholm, 1998; Mayers et al., 2005) and were reluctant to admit practical difficulties imposed by their deteriorating health (Ciambrone, 2003). Further, where capacities were undeniably impaired, some women reconstructed motherhood as a "virtual activity", emphasising supervisory and emotional aspects of parenting rather than the physical requirements that they could no longer consistently meet (Sandelowski et al., 2003; Van Loon, 2000). Motherhood therefore had paradoxical effects, adding to the physical, emotional and social burdens of HIV-infected women while simultaneously serving as a source of self-esteem and motivation (Doyal et al., 2005; Sandelowski et al., 2003).

Similarly, potential motherhood was a source of identity and legitimacy for many women, as suggested by the large proportion of infected women who wanted to have further children (Doyal et al., 2005). Bungener et al. (2000) reported that 43% of African and 31% of European French women wanted another child, while Mellers et al. (1994) reported that 29% of their French and British sample wanted more children. However, perhaps a more important finding reported by Wesley (2003) in a controlled comparison study is that desire for children did not vary according to HIV status. Rather being older, having had fewer abortions and being more religious predicted increased desire for children in general, while increased self-efficacy was associated with desire for children in infected women (ibid).

As noted earlier (in section 2.5.3), mothers were concerned about the potentially negative implications of parenting with HIV. In particular, they feared disclosure of their HIV status to their children and children's responses, worried about children assuming adult roles caring for their mothers and other family/household members, and were concerned about childcare, especially when their disease worsened and/or in cases where children were infected themselves (Gillman et al., 1996; Hackl et al., 1997; Mayers et al., 2005; Sandelowski et al., 2003; Sherr et al., 1997).

Research amongst both infected (Bauman et al., 2002) and non-infected women (Jones, Forehand, Brody, & Armistead, 2002) has shown that maternal depression predicts poor monitoring of children. However, there is not a simple inference to be drawn from this fact

and the added evidence of elevated rates of depression in infected women. Instead the picture is more mixed. There is evidence that infected mothers and caregivers engage in lower levels of effective parenting behaviours including: reduced parental support for the child, fewer efforts at discipline and supervision more generally, changes in family routines, and lack of attention or parental absence due to reorganisation of the family around illness (Armistead et al., 1995; Fair, Spencer, Weiner, & Riekert, 1995; Forehand, Armistead, Morse, Simon, & Clark, 2001; Kotchick et al., 1997).

However, research has also tended to show that disruptions are most evident in parents with advanced disease, and thus that the stage of the caregiver's illness rather than HIV status per se is associated with the quality of the caregiver-child relationship (Black, Nair, & Harrington, 1994; Hale, Holditch-Davis, D'Auria, & Miles, 1999; Johnson et al., 2001; Peterson, Drotar, Olness, Guay, & Kiziri-Mayengo, 2001). Moreover, there is research indicating that infected mothers become more tolerant and involved than before infection (Black et al., 1994; Peterson et al., 2001), shifting their focus to spending more quality time with their children and perceiving an increased importance in maintaining a positive relationship (Tompkins et al., 1999).

Just as mothering with HIV is complex and contradictory, so too are the implications for women's caregiving relationships.

2.6.2 Care and mothering as predictors of psychological adjustment

Several studies have examined associations between HIV-infected women's adjustment and motherhood per se as well as characteristics of the mothering or caregiving role. Of the four studies that tested the impact of having children on psychological distress, two found an association and two did not. Sherr et al. (1997) and Tompkins et al. (1999) reported that having children was not associated with suicidal ideation or levels of depressive symptoms in infected women, respectively, while Te Vaarwerk et al. (2001) and Reece et al. (2004) reported an association between having a child and psychological distress and levels of depressive symptoms, respectively. Similarly, while Simoni et al. (2000c) reported that infected mothers with an HIV positive child experienced better psychological adaptation

than mothers with non-infected children, two other studies failed to find an association with maternal mental health (Bennetts et al., 1999; Mellins et al., 1997).

All other characteristics of women's care roles assessed were predictive of psychological wellbeing: having a greater number of dependents was associated with higher levels of anxiety and depression (Van Servellen et al., 2002); higher levels of maternal role difficulty were independently associated with higher levels of depression (Milan et al., 2005); greater childcare demands strongly predicted psychological distress and psychiatric symptoms (Mellins et al., 2000); putting off going to the doctor due to caring for someone else reported higher levels of psychiatric disorder (Sherbourne et al., 2003); and having a child in the same household predicted higher global distress (Reece et al., 2004). However, research has also found that not having a child at home to care for predicted higher levels of depression (Reece et al., 2004), and a larger number of children living at home was associated with lower psychological distress (Sharts-Hopko et al., 1996). One possible explanation, particularly for the latter finding, is that amongst IVDU who made up much of the sample, higher distress and morbidity is likely to be associated with children being removed from one's care, hence the association between lower distress and a larger number of resident children.

2.7 OTHER PSYCHOSOCIAL ISSUES: QUANTITATIVE AND QUALITATIVE EVIDENCE

2.7.1 Key psychosocial problems

2.7.1.1 Psychosocial issues in general

Aside from concerns related to parenting and childbearing discussed in the previous section, several other important psychosocial issues for infected women are articulated in the research, many on the basis of qualitative evidence.

One set of concerns relates to women's HIV-related health, including the the need for HIV related information (Hackl et al., 1997) and concerns regarding antiretroviral medication

(Bunting, 2001; Doyal et al., 2005; Gillman et al., 1996; Goggin et al., 2001; Marcenko et al., 1999; Sowell et al., 1997). Several studies supported the role of death, dying and despair (Gillman et al., 1996; Hackl et al., 1997; Sowell et al., 1997), the sense of a lost future and frustrated plans (Bungener et al., 2000; Goggin et al., 2001; Sherr et al., 1997), and the loss of support and the death of loved ones to AIDS (Goggin et al., 2001; Semple et al., 1993; Sherr et al., 1997).

Goggin et al. (2001) and Hackl et al. (1997) also reported stigma as an issue for HIV-infected women. One study conducted with rural African American women reported that 58% of women were ashamed of their illness, while a substantial 40% felt looked down on due to their illness (Sowell et al., 1997). Women with an AIDS diagnosis experienced significantly higher levels of shame (ibid).

Infected women have also reported psychosocial problems not necessarily related to their HIV status, which in most cases predated their HIV diagnosis. For example, recovery from addiction was a concern for some infected women in the US (Gillman et al., 1996; Marcenko et al., 1999). Broader concerns raised in several studies were inadequate housing (Gillman et al., 1996; Marcenko et al., 1999) and financial strain (Gillman et al., 1996; Semple et al., 1993; Smith et al., 2001).

2.7.1.2 The impact and relative importance of psychosocial issues

In order to elicit the key psychosocial issues for infected women, some researchers have taken the approach of asking participants to list and/or rank their primary life stressors and concerns either independently of, or specifically in relation to, their HIV status. One such study that included a control group of non-infected African American women found that money was the most frequently mentioned problem among both infected and non-infected women and amongst equal numbers of women (15 and 14.8% for infected and non-infected women respectively) (Smith et al., 2001). Further, while HIV was ranked second among infected (predominantly asymptomatic) women, health was not a significant concern for non-infected women (ibid).

Other studies have taken the approach of women either comparing and contrasting concerns both before and after diagnosis, or listing both HIV and non-HIV related concerns. Similar to the above finding, Gillman et al. (1996) found that women listed financial problems as their most frequent concern both before (60%) and after (46%) diagnosis, while housing also remained a significant problem (48% before and 41% after diagnosis). However, after diagnosis, HIV health issues (38%), death and dying (37%) and children with HIV (32%) emerged as concerns for a significant proportion of women.

Another important finding corroborated by evidence from both the US and France is that HIV, in comparison with other experiences, is a significant issue for HIV-infected women. Bungener et al. (2000) reported that more than half of the women in their sample perceived HIV positive women as having specific problems, while Semple et al. (1993) found that 58% of the women in their sample identified an HIV related event, particularly learning of one's status, as their most stressful life event. However, an important qualifier to the latter finding is that this sample consisted of predominantly white, well-educated women, half of whom were employed and none of whom had a significant history of drug use. Clearly, this is likely to have impacted on their perceptions of HIV in relation to their lives as a whole and would account for the fact that housing and drug addiction that emerged as issues in other samples (of low-income ex-IVDU (for example, Gillman et al., 1996; Marcenko et al., 1999)), were either irrelevant or lacked salience for these women.

Ciambrone's (2001; 2003) research specifically addresses this issue, demonstrating that women who viewed HIV as the most disruptive event in their lives were more likely to be white, non-drug users[23]. Further, a more recent diagnosis, having AIDS, having negative reactions to disclosure, not knowing other PLWHA, and not having a partner also predicted experiencing HIV as disruptive. Thus for poor, predominantly African American women, many of whom (in the US) were previously drug users, HIV was likely to be just one in a series of disruptive life events and not necessarily their most pressing concern (ibid; Weinberg et al., 2004). While such women viewed HIV as a threat to their attempts

[23] Ciambrone's research can also be located in another body of work on illness narratives in general (Frank, 1995; Kleinman, 1998) and in the context of HIV specifically (Crossley, 2000; Davies, 1997; Ezzy, 2000; Soskolne, 2003). Due to the particular relevance of this research for the qualitative analysis, it will be presented in more detail in Chapter 5. This decision was taken in order to enhance the clarity and readability of the dissertation despite the substantive difference in presentation required of the two component studies (quantitative and qualitative) within the triangulated research design.

to lead "normal" lives after recovery, on reflection, they nonetheless considered HIV to be less devastating than the disruptions and losses they had experienced previously (Ciambrone, 2001). Further, many expressed the desire for others to view HIV as only one aspect of their identity, just as they viewed HIV as one part of their life trajectories.

For such women (as argued in Chapter 1), HIV/AIDS is typically an additional stressor for individuals, families and households already at risk due to a range of poverty-related factors, of which drug-use is just one. As Stewart, Cianfrini and Walker (2005) and Koopman et al. (2000) reported, lack of housing stability and lower income (both a function of poverty levels) was associated with higher perceived stress in PLWHA. Further, several studies found an association between higher levels of depression and negative life events, community risks and inadequate income that are likely to be endemic in poverty environments (Jones et al., 2002; Olley, Seedat, Nel, & Stein, 2004b).

The nature of women's environments is therefore an important factor when considering both the experience of HIV in general and the more specific impact on psychological adjustment. This is particularly important when untangling more long-standing psychological risk factors in a given population (e.g. poverty, drug use) that likely predate HIV infection but may exacerbate the course or response to living with a positive diagnosis.

2.7.2 Positive outcomes of diagnosis

While the above literature referred to HIV as an equally or sometimes less stressful event for women than other life experiences, there is also research that reports positive outcomes for women diagnosed with HIV. Despite the many challenges they face and the concerns they experience, some women from a range of sociocultural and economic backgrounds reported an improved sense of self as well as other positive shifts (Ciambrone, 2003; Dunbar, Mueller, Medina, & Wolf, 1998; Goggin et al., 2001; Weinberg et al., 2004).

Amongst Dunbar et al.'s (1998) sample, 39% of whom had some college education, 82% reported experiencing an unexpected positive outcome while living with HIV. Almost all of Goggin et al.'s (2001) sample of women (one in five of whom had a history of drug use)

reported at least one positive event subsequent to diagnosis. Women have reported reevaluating their priorities and gaining a new sense of meaning, purpose, self-awareness and self-acceptance (Weinberg et al., 2004). For some women this manifested in their attempts to redefine and rebuild relationships, including strengthening family ties (Dunbar et al., 1998; Goggin et al., 2001; Owens, 2003; Weinberg et al., 2004). Others reported that they took better care of themselves as opposed to others as in the past (De Marco et al., 1998; Dunbar et al., 1998; Goggin et al., 2001) or became more spiritual, often due to coming to terms with the possibility of their own death (Dunbar et al., 1998; Goggin et al., 2001). In addition, some women reported making healthier lifestyle choices, including establishing a positive support network (Goggin et al., 2001); adopting safer sexual practices and ending drug use (Goggin et al., 2001; Weinberg et al., 2004); and experiencing a sense of satisfaction and accomplishment from an HIV/AIDS- related job (Goggin et al., 2001).

In many cases, as Ciambrone's (2003) research illustrates, such outcomes were the result of women's struggle to find a "legitimate" place for HIV infection in their lives. Further, for women from particular cultural backgrounds, an inner strength and resiliency emerged that facilitated positive adjustment in the present despite being indicative of past difficulties and struggles (Weinberg et al., 2004). One study identified the availability of accurate knowledge; an accepting non-judgemental response from others; emotional, spiritual and social support; as well as self-determination and the passage of time as factors that facilitated and promoted this process (Dunbar et al., 1998).

2.8 THE MENTAL HEALTH IMPLICATIONS OF HIV/AIDS IN AFRICA AND SOUTH AFRICA

2.8.1 Psychiatric morbidity and psychological symptoms

A brief overview of the studies reviewed in this section is provided in Table 2.1 below. Further details regarding the findings of each study are included in the text that follows.

Table 2.1 Overview of African and South African research on HIV and mental health

Study	Focus	Country	Population, sample size	Method/ tools
Studies focusing specifically on women:				
Olley et al. (2006)	Psychiatric morbidity	South Africa	105 HIV− black recently diagnosed women (51 at 6-month follow-up)	MINI International Neuropsychiatric Interview (MINI)
Mast et al. (2004)	Quality of life	Uganda	803 rural mothers of young children (239 HIV+, 564 HIV-)	Culturally adapted version of Medical Outcomes Survey-HIV (MOS-HIV)
Keogh et al. (1994)	Psychosocial experiences	Rwanda	55 HIV− women (47 at 3-yr follow-up)	Questionnaire, including some questions adapted from DSM diagnostic criteria
Van Wouldenberg (1998)	Psychosocial experiences	Zimbabwe	19 HIV− women members of HIV-related support organisation	Ethnographic fieldwork/observation, including in-depth interviews
Nashandi (2002)	Psychosocial experiences	Namibia	12 HIV− women and 5 key informants	Focus groups and in-depth interviews
Austin (2003)	Psychosocial experiences	South Africa	50 HIV+ adult black African women	Questionnaire (no standardised scales included)
Studies including both men and women:				
Maj et al. (1994)	Psychiatric morbidity	Zaire and Kenya	Zaire: 205 adults (120 HIV−, 85 HIV-); 43% female Kenya: 203 adults (138 HIV+, 65 HIV-); 31.5% female	Composite International Diagnostic Interview (CIDI), Brief Psychiatric Rating Scale (BSR), Montgomery-Asberg Depression Rating Scale (MADRS)
Carson et al. (1998)	Psychiatric morbidity	Kenya	215 working adults (77 HIV+, 138 HIV-); 23% female	Clinical Interview Schedule (CIS) – Modified version, Neuropsychological test battery
Bganya (1999)	Psychiatric morbidity	South Africa	115 HIV+ black African adults; 70% female	Beck Depression Inventory (BDI), clinical assessment
Els et al. (1999)*	Psychiatric morbidity	South Africa	100 HIV+ black African adults; 57% female	MINI, Hamilton Anxiety Scale and Zung Self-Rating Anxiety Scale

Study	Focus	Country	Population, sample size	Method/ tools
Studies including men and women (continued):				
Sebit et al. (2003)	Psychiatric morbidity	Zimbabwe	194 adults (115 HIV+, 79 HIV-); 73% female	CIDI, MADRS, Mini Mental State
Olley et al. (2004a)*	Psychiatric morbidity	South Africa	149 HIV+ black recently diagnosed adults; 70% female	MINI
Shisana et al. (2005)	Psychological distress	South Africa	689-1010 HIV+ and HIV- youth and adults (>15 years); approx. 51% female[24]	Five statements adapted from screening section of the CIDI
O'Keefe & Wood (1996)*	Quality of life	South Africa	248 adults (134 HIV+, 114 in untested comparison group); 40% female	Medical Outcomes Study 36-item Short-Form Health Survey (SF-36)
Jelsma et al. (2005)*	Quality of life	South Africa	117 HIV+ adults on HAART (fewer numbers up to one-year follow-up); 70% female	EQ-5D (Quality of life scale)
Wilk & Bolton (2002)	Depression	Uganda	50 adults (HIV unknown) and 20 key informants	Free-listing and key informant interviews
Kaharuza et al. (2006)	Depression	Uganda	1017 HIV+ adults undergoing ART screening; 77% female	Centre for Epidemiologic Studies Depression Scale (CES-D)

* Also report on gender differences in outcomes

[24] The exact details of the sample to which the five mental health proxy measures were administered are unclear from the report. With regard to the section of the questionnaire that pertained to mental health, different sample sizes are reported for each of the five questions (see pp. 109-111 of the report). The report does not comment on the reason for this, hence the sample size is reported as the range across the five questions, i.e. from 689 to 1 010. What is known is that females comprised 51% of the the overall survey sample, which included a proportion of individuals that tested HIV negative; and that the overall questionnaire was administered to persons 15 years and older. Shisana et al. (2005) also caution that some of the participants that reported their status as HIV negative may have tested positive during anonymous testing.

2.8.1.1 Women's morbidity and gender differences

Overview of available research

As noted earlier, the available research on HIV-infected women from Africa in general and South Africa specifically is extremely limited, particularly when the lens is focused on empirical studies of mental health and psychological wellbeing[25]. Only two studies focus exclusively on women. One is a large-scale cross-sectional survey on the quality of life of HIV-infected and non-infected women in a rural district in Uganda (Mast et al., 2004). The other is a six-month longitudinal study on psychiatric morbidity amongst recently diagnosed HIV-infected women in Cape Town, South Africa (Olley, 2006). Further, in an earlier paper, the latter authors report on gender differences within the study's broader sample of both men and women (Olley et al., 2004a).

Beyond these, three studies conducted in South Africa on psychiatric morbidity (Els et al., 1999) and quality of life (Hughes, Jelsma, Maclean, Darder, & Tinise, 2004; Jelsma, Maclean, Hughes, Tinise, & Darder, 2005; O'Keefe & Wood, 1996) comment on gender differences in wellbeing. One study in Rwanda and another in South Africa on the social impact of HIV on women also reported on symptom experiences relevant to the assessment of depression (Austin, 2003; Keogh, Allen, Almedal, & Temahagili, 1994).

Of more tangential relevance, two qualitative/ethnographic studies with infected women in Zimbabwe and Namibia were sourced that report women's emotional difficulties as a result of being diagnosed positive and living with HIV (Nashandi, 2002; Van Woudenberg, 1998). There are likely several other reports similar to the latter within the grey literature that could not be sourced. However, their contribution to the present review would be limited.

[25] See Meel (2006) for a recently published case report of an HIV-positive South African woman with a psychiatric disorder who was sexually assaulted.

Prevalence of psychiatric symptoms and disorders

Olley and colleague's (2006) research described above drew on a sample of women of whom half were asymptomatic and 3% were receiving antiretroviral therapy. The women were mostly unemployed (77%), single (53%) and without children (65%). Of the combined sample of men and women, the latter constituted 70% (Olley et al., 2004a). Fifty-six percent of the sample met the clinical criteria for at least one psychiatric disorder. Rates of major depression (35%), dysthymia (23%), PTSD (19%), alcohol use disorders (4-5%) and suicidality (11%) were found. The rates at follow-up indicated a modest decline in psychiatric diagnoses in general, with rates of 51, 22, 2 and 8% for psychiatric morbidity, major depression, dysthymia and suicidality (Olley, 2006). Rates of PTSD at follow-up were, however, considerably higher at 29%.

Mast et al. (2004) conducted a study of 803 HIV-infected mothers of young children (6 months to 3 years) in the rural Rakai District in Southwest Uganda. Women reported levels of quality of life comparable with South African data. Just over 22% reported feelings of depression while 16.3% reported being so depressed that nothing could cheer them up.

Three qualitative studies also explored mental health experiences as part of a broader psychosocial focus. A study conducted in Rwanda in the early 1990s found that two in three HIV-infected women reported no difficulty with sleep, performing daily routines or having feelings of depression at any time since testing positive (Keogh et al., 1994). However, nearly half reported losing pleasure in things they usually enjoyed, suggesting that levels of sub-syndromal, if not clinical, depression may have been prominent. Similarly, 70% of poor, black South African women in another (unpublished) study reported feeling depressed, while nearly half had experienced suicidal ideation at the time of diagnosis (Austin, 2003). Both sets of findings are largely consistent with evidence regarding infected women in Zimbabwe, most of whom reported experiencing periods of not coping (Van Woudenberg, 1998).

Psychosocial, sociodemographic and health-related predictors

Keogh and colleagues (1994) argue on the basis of interview data that not being legally married, having no income and avoiding thinking about HIV were the best predictors of self-reported depressive symptoms in HIV-infected Rwandan women, while higher viral loads and a higher number of physical symptoms were associated with greater depression and poorer quality of life amongst Ugandan women living with HIV (Mast et al., 2004).

Olley's research provides support for only some of these findings although comparison is limited by the different set of predictors examined across the studies. Overall, the extent of disability experienced and not CD4 counts was the best and most consistent predictor of depression, dysthymia and PTSD, even when controlling for the effect of other variables (in multivariate analysis) (Olley, 2006; Olley et al., 2004b). Further, the association between disability and PTSD and depression held at a six-month follow-up, as did the relationship between the number and severity of negative life events and depression (Olley, 2006). Other findings reported were that depression was associated with being unemployed and being female (Olley, 2006; Olley et al., 2004b; Olley, Zeier, Seedat, & Stein, 2005), while lack of social support was associated with dysthymia (Olley, 2006), and being female and being sexually violated was associated with higher levels of PTSD (Olley et al., 2004b; Olley et al., 2005).

Other findings with regard to impact of gender have also been reported. Olley et al. (2004a) found that rates for women were higher than men for PTSD (19 vs. 5%) and lower for alcohol use (4-5 vs. 20-23%). While no differences were detected in affective disorders, the sample's power may have been a limitation in this regard (ibid). Panic disorder was also reported as more common in women in an earlier study conducted in Bloemfontein with an almost entirely black African sample (Els et al., 1999), while African females in Cape Town reported significantly lower levels of quality of life than men or white females, including general mental health and limitations in social and usual role activities due to physical or emotional problems (O'Keefe et al., 1996). A more recent quality of life study conducted in Cape Town with people on HAART, however, failed to report differences between men and women (Jelsma et al., 2005). Substantive differences in the populations and methods of these studies constrain comparisons.

2.8.1.2 Morbidity in adults

Given the paucity of studies on psychiatric morbidity in HIV-infected women in Africa, a brief synopsis of studies with men and women (as recorded in Table 2.1 above) is necessary in order to adequately locate the current study in relation to previous research in South Africa and other African countries.

Data from other African countries

Morbidity data for Africa is drawn from four studies: one conducted in Zaire and Kenya in the early 1990s (Maj et al., 1994), one conducted in Kenya in the late 1990s (Carson, Sandler, Owino, Matete, & Johnstone, 1998), and two conducted more recently in Zimbabwe (Sebit et al., 2003) and Uganda (Kaharuza et al., 2006). All four employed previously validated self-report or diagnostic instruments. While the two more recent studies included samples consisting of predominantly women and found high rates of psychiatric disorder and distress, the two earlier studies included mostly men and reported much lower rates.

Maj et al.'s (1994) WHO survey that included two sites in Africa (Zaire and Kenya) reported low rates of current and lifetime psychiatric morbidity. Between 0 and 6.9% of adults (across the sites) met the criteria for at least one diagnosis, while rates of major depression were reported as 0-5.5%, dysthymia 0-1.5% and generalised anxiety disorder 0-7.1%. Lifetime prevalence was only slightly higher, with overall morbidity reported at 4.7-11.1% and the highest individual rates reported for depression (2.3-9.7%). While neither HIV status nor disease severity were associated with differences in clinical prevalence, symptomatic men and women reported significantly higher levels of self-reported depression and anxiety than seronegatives, but not those who were asymptomatic (ibid). Amongst Carson et al.'s (1998) Kenyan sample, no significant differences between infected and non-infected adults were reported based on an assessment of the frequency of psychiatric symptoms. Rates for depression and anxiety and worry amongst the infected group were 12 and 13% respectively.

In contrast, Sebit et al. and Kaharuza report much higher rates of morbidity. Amongst the 1017 infected Ugandan adults, 47% reported high levels of depressive symptoms (Kaharuza et al., 2006), while 57% of Sebit's (2003) Zimbabwean sample were depressed and 71% presented with some form of psychiatric disorder. Kaharuza et al. also reported that a CD4 count of less than 100 most strongly predicted depression (regardless of whether somatic items were included), while being a woman, being older than 50 years, and not having an income source were also risk factors. Using a control group of HIV negative community members, Sebit et al. established that levels of overall morbidity, depression and alcohol use and misuse were higher amongst infected than non-infected adults. The fact that the Ugandan and Zimbabwean studies were conducted nearly ten years after the WHO survey, at the height of the pandemic, and included mainly women who were disproportionately affected by HIV, must be considered factors accounting for the higher mental health burden in these studies compared with Maj et al.

Another study conducted in Uganda also provided support for the relevance of depression in PLWHA, although employing a very different methodology (Wilk & Bolton, 2002). Based on a free listing exercise conducted with 50 locals and 20 key informant interviews, eight psychological experiences associated with living with HIV were identified that were largely encompassed in two local syndromes. Of relevance is the fact that these syndromes covered all major clinical criteria for depression, as well as some additional symptoms not part of Western definitions of depression. These symptoms may have reflected culturally specific manifestations of, for example, social dysfunction (ibid). No symptoms of PTSD emerged.

South African data on psychiatric morbidity

Data from five[26] South African studies provide further evidence regarding the relevance of depression and other psychiatric disorders in HIV-infected people. This research generally reported levels much higher than in the WHO Africa survey (Maj et al., 1994), but more

[26] In a small study based on a convenience sample, Botha (1996) reported average or below average scores for affective disturbance (and above average scores for posttraumatic stress reactions and somatic focusing). However, since the paper provided no information regarding site, sample composition, scales used or the norms on which the analysis was based, the study's results have not been included in the review.

consistent with Kaharuza (2006) and Sebit's (2003) research as well as international, developed country figures.

In the two studies that assessed prevalence in a predominantly black, South African population, rates of major depression were reported at 35-38% (Bganya, 1999; Els et al., 1999), panic disorder at 37% (Els et al., 1999), generalised anxiety disorder at 21% (ibid), clinically elevated symptoms of anxiety at 31% (Els et al., 1999), dysthymia at 5% (Bganya, 1999), and adjustment disorder at 7% (Bganya, 1999). Further, more than half of one sample exhibited psychiatric comorbidity (Els et al., 1999). Bganya (1999) also noted, importantly, that somatic symptoms were commonly reported, while affective symptoms were reported more often by those with clinically elevated scores. While this suggests that affective as opposed to somatic symptoms better differentiate clinical depression (as opposed to general distress), Bganya provided no analysis in his report to support the conclusion that he draws.

Three other studies also reported relatively high rates of self-reported depression and anxiety, although the measurement tools used provide a less rigorous assessment of mental health. Shisana et al.'s (2005) nationally representative sample employed five statements adapted from the screening section of a diagnostic tool (the Composite Diagnostic Interview – CIDI) as proxy measures. Based on this assessment, 42% of HIV-infected adults reported feeling sad, empty or depressed, while 33% had problems sleeping and 25% felt anxious.

In the other two cases, the quality of the data is instead a reflection on the fact that the research focused on health-realted quality of life, of which mental health is one only component. Baseline figures in Jelsma et al's longitudinal study with people on HAART in a poor urban community ranged from 31.6% at the commencement of treatment, to 17.6% at 1 month, 20.6% at 3 months, 17.4% at 6 months and 14.5% at 12 months (Jelsma et al., 2005). Jelsma et al. (2005) reported that there was no difference between controls and HIV-infected people starting HAART, but that an improvement in anxiety and depression, as well as other aspects of quality of life, were noted in HAART patients after one year, with the most improvement evident at 3 months. However, it is also noteworthy that even following an initial rapid improvement, people on HAART still perceived their health as

poorer than a matched community sample (some of whom may have been HIV positive) (ibid). O'Keefe and Wood's (1996) findings indicated poorer mental health, although direct comparability of findings is limited given numerous differences in method. HIV negative adults rated their mental health at 75/100 while HIV positive men and women rated their mental health between 58 and 61/100. These figures are comparable with more recent data reported by Mast et al. (2004) for HIV-infected women in Uganda (as mentioned earlier).

Other potential predictors of morbidity and adjustment are also worth reporting, despite not emerging from a consistent body of evidence. South African researchers have shown that being HIV positive is associated with poorer mental health (O'Keefe et al., 1996) and greater symptoms of depression (Shisana et al., 2005), while no differences in anxiety were reported as a function of HIV status (ibid). Other evidence indicated that longer time since diagnosis was associated with diagnoses of dysthymia, bipolar disorder, agoraphobia and social phobia (Els et al., 1999); being single is a predictor of elevated levels of depressive symptoms (Bganya, 1999); and generalised anxiety disorder is more common in older people and bipolar mood disorder in younger people (Els et al., 1999). Further, with regard to stage of disease, while Bganya (1999) reported that having AIDS predicts elevated levels of depressive symptoms, Els et al. (1999) and O'Keefe and Wood (1996) found greater distress present in early stage disease, both quality of life in general and rates of depression and dysthymia.

2.8.2 Disclosure, social support and coping: Studies from South Africa and elsewhere on the continent

2.8.2.1 Disclosure

Available research on women's HIV-related disclosure is very limited, at least with regard to rigorous, published evidence based on more large-scale studies. Of the studies reviewed, four qualitative studies reported on women's disclosure (Austin, 2003; Nashandi, 2002; Van Woudenberg, 1998), although only one had disclosure as a key focus (Almeleh, 2006) and none appeared in peer-reviewed journals. One other longitudinal study used semi-structured interviews to generate quantifiable data regarding disclosure and was published

(Varga, Sherman, & Jones, 2005)[27]. Also included were: a review paper that covered data from 14 countries in sub-Saharan Africa (Medley, Garcia-Moreno, McGill, & Maman, 2004), comments on unpublished data (Aids and Society Research Unit, 2004/5 in Almeleh, 2006), and two conference papers (Forsyth et al., 2005; 2006). Although not yet published, the latter two papers were based on a large-scale study (n=293), included a substantive examination of disclosure, and (at the time of presentation) included a 3-month follow-up. The fact that the study focused on recently diagnosed pregnant black African women rendered it useful research in the South African context. However, it may not address the experiences of the large number of poor women infected at other times of their lives.

Rates and experiences of disclosure

Rates of disclosure to partners in developing countries (14 out of 15 of which were in Sub-Saharan Africa) have been reported as wide ranging as 17-86%, with disclosure occurring from two weeks to four years following diagnosis (Medley et al., 2004). Very low rates were reported by women in two small, qualitative studies conducted in Zimbabwe and Namibia, with many women in the one study failing to disclose publicly (Nashandi, 2002; Van Woudenberg, 1998). However, the particular context of these studies, namely, areas where there was considerable ignorance regarding HIV and a lack of services should be borne in mind.

Three South African studies also reported on the disclosure of women living with HIV. One of the studies reported that women were most likely to disclose to their partner first (38%) followed by parents (30%) (Austin, 2003). Fourteen percent of women disclosed their HIV status to their children (ibid). A study with a small group of peer educators in Cape Town found that women disclosed most frequently to mothers and sisters, followed by siblings, other family members, partners and friends (Almeleh, 2006). Following up a convenience sample of 31 women evaluated for vertical transmission, Varga, Sherman and Jones (2005) reported that all but three mothers had disclosed their status on initial interview and all but two one year later. For nearly two-thirds of the women, their first

[27] One other published South African study was not included since it only focused on disclosure as a factor that influenced adherence to antiretroviral therapy (Skhosana, Struthers, Gray, & McIntyre, 2006).

disclosure was to a partner or husband, while secondary targets were usually immediate female family members (ibid).

With the exception of the two African studies conducted in areas with particularly poor knowledge of HIV (Nashandi, 2002; Van Woudenberg, 1998), most studies did not report overly negative reactions to women who disclosed their status. Recently diagnosed pregnant women in Forsyth et al.'s (2006) study reported that 19% had felt hurt by people's reactions, while only seven (4%) had either lost a friend or been physically hurt as a consequence of disclosure. Similarly, Varga et al. (2005) reported that most pregnant women in her sample who disclosed voluntarily described the response as constructive and supportive, while unpublished data from a broader sample of people on HAART suggested that most received positive support from household members to whom they disclosed (Aids and Society Research Unit, 2004/5 in Almeleh, 2006). Across the region, available evidence indicated that between 4 and 28% of women who disclosed to partners reported some negative experience, including blame, abandonment and violence.

Factors associated with disclosure

Some of the above studies have also investigated factors associated with women's disclosure, including factors that differentiate disclosers from non-disclosers. Taken together this evidence indicated that: younger women, women of lower socioeconomic status, women who had been in a relationship longer, women who personally knew someone with HIV, and women with more education were more likely to disclose to a partner (Medley et al., 2004). Recently diagnosed pregnant women were more likely to disclose their status if they were married, had prior discussions about testing and knew someone who was HIV positive (Forsyth et al., 2006). Forsyth et al. (2005) failed to find any differences between disclosers and non-disclosers with regard to levels of social support, depression and sense of coping.

One of the important contextual factors likely to influence disclosure is the levels of stigma and discrimination in a given community. Recent research conducted in Cape Town, South Africa showed that most adults (94%) and young adults (97%) expressed some degree of negative behavioural intentions or stigmatising attitudes towards PLWHA, with 29 and

46% of them expressing moderate to high levels of stigma respectively (Maughan-Brown, 2006a; 2006b). Further, the prevalence and magnitude of stigma was a function of the dimension of stigma considered[28], with symbolic stigma (moral judgements such as blaming PLWHA for becoming infected) and instrumental stigma (attitudes or beliefs based primarily on fear of infection, such as not sharing eating utensils due to concerns about catching HIV) expressed more often and to greater degrees than negative behavioural intentions towards PLWHA. While these figures were considerably higher than those reported in previous surveys in South Africa (Parker, Oyosi, Kelly & Fox, 2002 in Maughan-Brown, 2006b; Shisana et al., 2005), this was attributed to the fact that only those aspects of stigma found to be least prevalent in Maughan-Brown's (2006a; 2006b) studies, namely, behavioural intentions towards family/friends, were considered in the earlier surveys.

While clearly women's decisions not to publicly disclose may be influenced by stigma and negative community attitudes, Almeleh (2006), writing in the South African context, stressed that disclosure occurs within specific relational contexts and must be understood as mediated by the dynamics of those relationships. Further, Varga et al. (2005) pointed to the dynamic nature of disclosure, reporting that while partners were ultimately sympathetic following disclosure, this often followed initial anger, upset and even temporary rejection. Health and treatment related factors are also likely to play a role. For example, Almeleh (2006) also reported that the visibility of the illness, influenced by its severity, was an important factor that influenced women's decisions regarding disclosure. Limited access to HAART (as noted earlier in section 2.5.2) may also deter disclosure in sub-Saharan Africa. However, the fact that disclosure to at least one person is sometimes a prerequisite to treatment access could play a moderating role.

2.8.2.2 Social support

Current research on social support consisted only of three qualitative studies and two quantitative ones, neither of which assessed social support using standardised scales. The two quantitative studies, both conducted in South Africa, reported that loss of support

[28] See Deacon, Stephney and Prosalendis (2005) for a more detailed discussion of the conceptualisation and measurement of HIV and AIDS-related stigma.

predicted clinically elevated levels of depression (Bganya, 1999) and that levels of social support did not vary as a function of HIV status (Olley et al., 2005). Social support did not emerge as a significant predictor of infected women's psychological adjustment in multivariate analysis (Olley, 2006). Additional findings were that women reported that 47.6% of family members were supportive, 25.7% of friends, and 30.5% of partners or husbands, with a slight improvement in levels of support over a six-month period, especially amongst family members (ibid).

Two qualitative studies, both in areas with very limited knowledge regarding HIV and services at the time (Namibia and Zimbabwe), reported that organisational support was important to infected women, with religion being a salient part of several women's support systems (Nashandi, 2002; Van Woudenberg, 1998). Rwandan women rated support from a priest as their second most important source of support, while not having a partner or family to care for their children was their greatest source of vulnerability (Keogh et al., 1994).

2.8.2.3 Coping

The role of religion in coping

In addition to deriving support through their religion, several studies refer to religion as forming part of women's coping strategies more generally. Olley (2006) reported that engaging in religious activities remained one of women's most used coping behaviors over a six-month period, and that women were more likely than men to use religious activities to cope (Olley et al., 2004a). Half of HIV-infected women in Rwanda who perceived themselves as having good morale attributed this to their religious faith (Keogh et al., 1994), while a small group of Namibian women experienced religion as their main coping strategy (Nashandi, 2002). Religion was also a strategy used by women in Zimbabwe (Van Woudenberg, 1998).

The potential for religion to contribute to stigma must, however, also be considered. For example, Maughan-Brown (2006a) reported that greater religiosity among some respondents was associated with higher levels of stigma. Although religious writers have

attempted to challenge this philosophy (Paterson, 1997), the moral values promoted by churches might be interpreted by some as legitimating blame and discrimination in relation to PLWHA.

Other coping strategies and associated factors

Van Woudenberg (1998) argued that women adapted coping responses depending on disease severity and context, and although emotion-focused coping such as acceptance, denial, religion, positive reinterpretation and emotional support were used most frequently, problem-focused coping was also employed. Olley (2006) similarly reported that HIV-infected women employed a range of strategies, with the most-used behaviour (aside from religious activities) being acceptance, seeking emotional support, seeking instrumental support and planning, while the least used strategies were humour, substance use, denial and self-blame. However, at a six-month follow-up (in the absence of any formal intervention), women were less likely to employ denial but more likely to use acceptance, emotional support, positive reframing and planning as a means to cope (ibid).

Van Woudenberg (1998) also reported a change in strategies over time: many women alternated between hope and mental disengagement, and found denial an insufficient strategy when their disease progressed. Nonetheless, a South African study reported that 70-80% of infected women used some form of avoidance to cope (Austin, 2003), while 22% of Rwandan women reported sustaining themselves by avoiding thinking about HIV (Keogh et al., 1994). Evidence regarding more adaptive strategies indicates that women were more likely to use planning than men (Olley et al., 2004a), and that living positively in the sense of "living 'for the day'" is an important coping strategy in itself (Van Woudenberg, 1998, p. 108).

2.8.3 Psychosocial problems

In a similar vein, three different South African studies addressed the issue of women's attempts to redefine their identity and life experience in light of a positive diagnosis. Both Austin (2003) and Soskolne (2003) found that most women in their low-income samples reported positive experiences consequent on, and subsequent to, their diagnoses. Ninety

percent of the women in Austin's sample viewed HIV as an opportunity to grow, while many of Soskolne's (small) sample of women who had received a narrative intervention were living with a re-affirmed sense of identity and with hope and acceptance regarding their status and the limitations it imposed. Diagnosis had, however, represented a "junction" or disruption in their lives that compelled them to shift community ties and redefine themselves, often in the context of previous traumas and losses that diagnosis re-evoked (ibid). Further, a more psychoanalytic analysis revealed that the women vacillated between conflicting notions of illness and health, empowerment and disempowerment, strength and weakness, and death and continuity (Soskolne, Stein, & Gibson, 2004). Like the women in Rohleder and Gibson's (2006) study (living in the same community), they were engaged in the difficult task of constructing a positive identity despite the presence of more vulnerable parts of themselves and negative implications of living with HIV.

More general concerns and issues regarding living with HIV were also reported by women in a study conducted in Namibia. These included: answering children's questions about ill health; negotiating socio-cultural demands to have more children, to have unprotected sex with husbands and to prioritise the care of others despite the risks to one's own wellbeing; and the challenge of finding and maintaining employment (Nashandi, 2002). Finances, poverty and/or unemployment was either the most important or a central concern for infected men and women in Uganda (Bolton & Wilk, 2004) and South Africa (Kalichman et al., 2003b), and for women in Rwanda (Keogh et al., 1994), Zimbabwe (Van Woudenberg, 1998) and South Africa (Olley, 2006). Unsurprisingly, socio-economic consequences and concerns were greatest for the poorest women (Keogh et al., 1994; Van Woudenberg, 1998). Thus where equal numbers of women have been reported to view HIV as their main problem as view other problems as more pressing, income was a significant predictor of attitude (Keogh et al., 1994). Infected women in Zimbabwe reported that it was necessary for them to focus on survival issues rather than HIV until they became ill and HIV became more salient than simply "a life event among others" (Van Woudenberg, 1998, p. 77).

Fourth, some women have reported that HIV is less distressing and significant for them than other stressors that they face on a daily basis, most notably chronic poverty.

Fifth, motherhood (and caregiving) is salient for many HIV-infected women and is often a source of self-esteem and wellbeing despite the parenting and other challenges that it imposes.

Finally, despite the many potentially adverse experiences and outcomes associated with living with HIV, many women are also able to derive a sense of meaning and renewal and/or display resilience in light of other more or equally difficult life experiences that they have faced.

2.9.2 Key contributions

In the first instance, given the chosen location in Cape Town, South Africa, the study will contribute to the evidence base for poor, infected women, in particular those in sub-Saharan Africa. Thus while some of the same questions were examined as have been in the US, only two published quantitative studies focusing exclusively on the mental health implications of HIV/AIDS for women specifically have been conducted in Africa or South Africa. One examined quality of life, of which mental health is a component (Mast et al., 2004), and the other psychiatric morbidity (Olley, 2006).

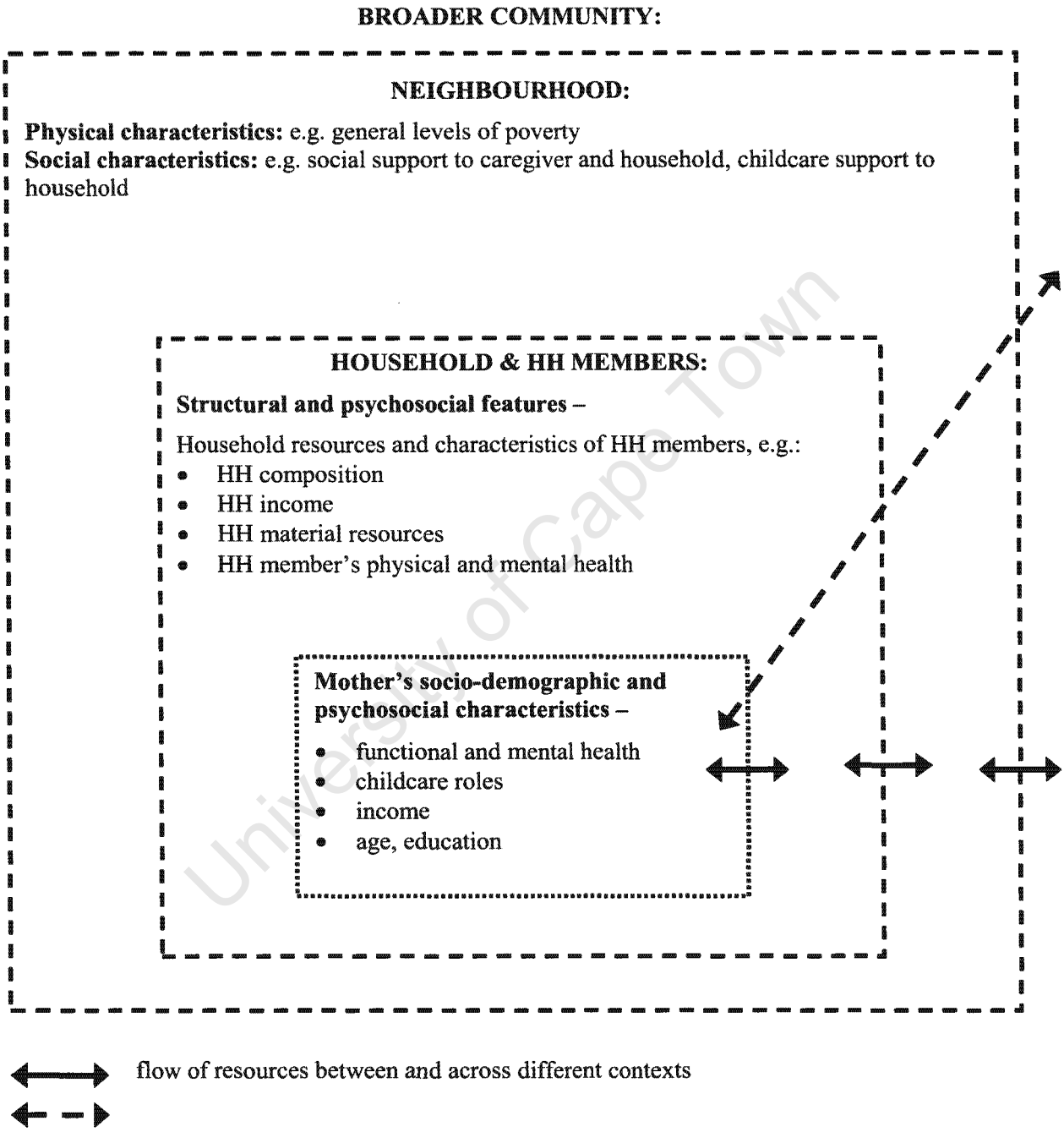
Two related conceptual points also emanate from the chosen context. In poverty environments in South (and southern) Africa, almost all women care for children. Women in mothering roles rather than women per se were the choice of focus since the former group experiences the added burden to mental health associated with providing care. They also constitute the large number of women living with HIV in the chosen community given the centrality of mothering. The present study will therefore contribute to the body of knowledge about women at greatest risk, namely, those that are living with HIV in addition to dealing with the challenges associated with poverty and childcare.

Further, both unemployment and cultural values centred on relatedness and shared or communal caregiving are common in the chosen context. Consequently, women/carer's

relationships with household members, extended kin and neighbours represent an important context for understanding women's caregiving roles as well as their functioning as individuals (Bray et al., in press; Henderson, 1999; Swartz et al., 2005). Since not all carers of children in the chosen setting were biological mothers, the study did not, like most other studies reviewed, employ the criterion of biological mother as its point of departure (see section 3.2.3.1 for further discussion). Instead women who adopted mothering roles despite the absence of a biological relationship with the child were also included.

This approach represents a small, but important cultural adaptation that acknowledges the importance of women's particular contexts for investigating their psychological wellbeing. While it is true that all HIV-infected women live in households and communities, the links between women and their households and communities are deeper and more salient in poor communities than in middle-class societies (Stack, 1974). Moreover, in developing world settings where poverty is endemic and HIV prevalence high, the mental health impact of the disease is even more likely to be felt by families, communities and societies as a whole, in addition to being felt by the infected individuals (Freeman, 2004). Individuals and households proximal to infected women are therefore quite possibly under strain. The present study therefore drew broadly on an ecological approach. This served to situate the psychosocial lens and positioned women as individuals as well as role players within a household, in the first instance, and a broader set of networks in the second instance that included but was not limited to family members (Bronfenbrenner, 1989). These key features of the study's conceptual design are depicted in Figure 2.1 below, in particular women's location within a series of embedded contexts (the household, neighbourhood and broader community) and the links and sometimes porous boundaries between these contexts. The links and boundaries are represented by the bidirectional arrows both between and across the contexts, as well as the dotted lines demarcating them.

Figure 2.1 A contextual model of mothers' psychological adjustment



This point regarding context leads to a series of methodological contributions that the study also intended to make. First, in order to locate women within their contexts (as described above), as well as to contribute to a gap in the research reviewed, a multivariate

study was conducted. Importantly, the design incorporated aspects of household socio-economic and psychosocial functioning as well as including many of the predictors considered in the review (see Table 3.2 in section 3.3.3 for further details).

In addition to a quantitative, multivariate study, a nested qualitative study was conducted in order to explore women in context in a less structured manner as well as to allow for aspects of living with HIV (from a psychological perspective) that might be unique to the context to emerge. The chosen approach that will be detailed further in Chapter 3 was also one that explicitly considered women's perspectives as an important adjunct to what a population-based approach could contribute to policy and planning. While a qualitative study was therefore felt to be an important component of the overall study, the inclusion of quantitative work was important theoretically and for reasons of audience. Given the stated objective to influence policy and planning, service providers were an important audience for the research and it was believed that a small-scale qualitative study alone was insufficient to adequately examine the issues needed to inform services and would likely be insufficiently persuasive.

Finally, two other intended methodological contributions also relate to service and research considerations: the purposive sampling of women on HAART and the inclusion of a control group. With regard to the latter, three other (published) studies to date have been conducted in South Africa employing comparison groups. However, one used only simple, proxy measures of mental health and was methodologically weak in that respect (Shisana et al., 2005), while the other two studies did not establish the seronegative status of the comparison group (Jelsma et al., 2005; O'Keefe et al., 1996). In contrast, the present study verified the HIV status of the control group as well as using a consecutive rather than convenience sample[29]. This represents a more scientifically rigorous approach to research. In addition, a controlled comparison study is particularly important in a setting such as South Africa where norms are typically not available for comparative analysis (of scores on standardised scales).

With regard to the role of HAART, there is very limited research that systematically addresses the role of HAART in determining psychological outcomes, and only one such

[29] See section 3.2.3 for further details.

study in Africa or South Africa (Jelsma et al., 2005). However, Jelsma's (2005) research objectives were different than those of the present study and as such, mental health was assessed as one aspect of quality of life using one item on a self-report scale. A matched community sample for which HIV status was indeterminate was also employed.

The present study will therefore produce new data in South Africa in two respects. First, it will be the first study to systematically examine the impact of HAART on mental health, and second, it will be the first study to investigate the relationship between HIV/AIDS and psychological adjustment using a verified control group. Given that the roll-out in South Africa is still in its relatively early stages, the research could therefore provide important empirically-sound information to drive policy and service planning with respect to mental health.

2.10 STUDY AIMS AND OBJECTIVES

The study focuses on the psychological adjustment of HIV-infected women and mothers in the era of HAART who live in poverty. It aims to investigate empirically whether differences exist in the psychological adjustment of infected and non-infected mothers. A secondary aim is to explore the impact of disease severity on adjustment. Both issues are underpinned by the question of whether being diagnosed HIV positive makes any discernable contribution to psychological wellbeing in the presence of a range of other poverty-related stressors, the contribution of which may already be significant.

Following on from this, the study aims to further deepen the response to this question by considering the role of HAART in determining psychological outcomes for infected mothers (both access to HAART per se and the duration of access). The role of a range of socio-demographic, care, health and mental health-related predictors is also investigated. An important part of this objective is to examine the relative impact of these factors when compared with mothers' HIV status.

Finally, the study aims to explore mothers' perspectives on living with HIV or AIDS in a poverty context. This objective is intended to dovetail with the previously mentioned ones

by deepening, complementing and contributing to the understanding of women's psychological adjustment developed through the quantitative approach.

Details regarding research questions and the motivation for certain decisions (for example, to examine psychological adjustment at six months on HAART) will be provided in Chapters 3 and 4. Operationalised for later analysis (in Chapters 4 and 5), the research questions driving the study are therefore as follows:

Research questions 1.1-1.2:
Does the psychological adjustment of mothers vary as a function of HIV status and/or disease severity?

1.1 Do HIV positive mothers exhibit poorer psychological adjustment than HIV negative mothers?

1.2 Is there a difference in the psychological adjustment of asymptomatic, symptomatic and AIDS-sick HIV positive mothers, and do they differ from HIV negative mothers?

Research questions 2.1-2.5:
Does being on highly active antiretroviral therapy (HAART) result in improved psychological adjustment for HIV positive mothers?

2.1 Does commencing HAART result in improved psychological adjustment?

2.2 Is there an improvement in psychological adjustment from the time that mothers commence HAART to six months on HAART?

2.3 After six months on HAART, do mothers exhibit better psychological adjustment than those without access to HAART?

2.4 After six months on HAART, have mothers returned to the levels of psychological adjustment exhibited by HIV negative mothers in their community?

2.5 Can psychological adjustment be predicted by changes in health (either perceived or actual) while on HAART?

Research question 3:
Which socio-demographic, poverty, care, health and mental health-related factors predict the psychological adjustment of HIV positive mothers?

Research questions 4.1-4.2:

4.1 Does HIV status predict the psychological adjustment of mothers after controlling for other relevant socio-demographic, poverty, care, health and mental health-related factors?

4.2 Does HIV status have more or less of a predictive effect on the psychological adjustment of mothers than socio-demographic, poverty, care, health and mental health-related factors?

Research question 5:
From a psychosocial perspective, what are mothers' personal experiences and views regarding living with HIV or AIDS in a poverty context?

CHAPTER 3. STUDY METHODS

Chapter 3 presents the methods used in the study, beginning with an outline of pilot work. This is followed by a presentation of the overall research design and details of the cross-sectional quantitative study and the longitudinal, qualitative case studies that were conducted. Finally, some issues regarding research ethics will be discussed.

3.1 PILOT WORK

Pilot work was conducted primarily for methodological reasons, namely to assist in the development of a theoretically sound research approach and contextually sensitive research tools. While the pilot also formed part of a larger project with a broader set of objectives and requirements, this chapter reports only on those aspects relevant to the development of the present study[30].

3.1.1 Site selection

Masiphumelele, a low-income peri-urban settlement in the Cape Peninsula, was chosen as the site for pilot work due to the fact that its socio-economic, demographic and HIV prevalence profile was representative of a large number of poor urban settlements in the Cape Town area. In addition, the community had a range of HIV-related services, including an antiretroviral programme.

3.1.2 Sampling strategy and description of sample

The study sample comprised five HIV-infected women who lived in Masiphumelele. The selection criteria for the study were that the women had been on antiretroviral therapy for not more than six months (and had therefore all been diagnosed as AIDS sick), and were

[30] For further details regarding the larger project see Swartz et al. (2005); for a more detailed write-up of pilot work see Brandt (2005a).

the primary caregiver of at least one child who was HIV negative and less than six years old[31]. The participants were all isiXhosa-speaking and ranged in age from 23 to 37 years. Their CD4 counts at the commencement of HAART ranged from 10 to 142. The women were identified randomly through the local HIV treatment centre with the help of medical staff, and informed consent was obtained for their study participation.

3.1.3 Research procedure

Two meetings were held with each woman: the first to administer a questionnaire and the second to conduct a semi-structured interview. All material was translated into isiXhosa, the predominant language spoken in the community. The questionnaire collected individual and household-level demographic information, a history of caregiving, and information about the caregiver's functional health. In addition, it included four standardised scales that were selected in order to assess maternal psychological adjustment, coping and social support[32]. The semi-structured interview was intended to allow for further exploration of some of the issues already covered in the questionnaire as well as to identify any other relevant issues that would be of interest for the study to be conducted.

3.1.4 Summary of results

Extensive details of the methodological refinements made in light of pilot data are provided elsewhere (Swartz et al., 2005). However, the following are some of the main points to emerge: First, household income alone could provide a false or reductionistic picture of economic viability due to the diverse and irregular nature of income in low-income households in South Africa. Consequently, it was decided to add questions regarding the receipt of non-monetary forms of support (e.g. food parcels) as well as questions likely to provide insight into the sustainability of households over time (e.g. regularity of income and food scarcity).

[31] Motivations for these choices are discussed in detail in Brandt (2005a).
[32] Further details regarding these instruments are provided in section 3.3.2.1.

Second, based on data gathering on the child's caregiving niche, it was decided to include a more comprehensive set of questions tapping not only women's care for children in their household, but unpaid care to non-biological children outside the household, and to adults in- and outside the household.

Third, with regard to social support, it was determined that satisfaction with support should be elicited for each item in the support scale rather than each category/type of support. Participants should also be asked to provide further details regarding those that they identied as part of their support network (name, sex, relationship to participant and residence). This would provide more detailed information regarding which kinds of relationships are most supportive to HIV-infected women and are predictive of healthy psychological adjustment.

Fourth, given that disclosure of HIV status emerged in the qualitative interviews as an issue with psychological significance for women, it was decided to include more detailed questioning regarding disclosure in the main study.

Finally, pilot data pointed strongly to the benefits of a multi-method approach. Further, the approach benefited from including an assessment over time (either through a longitudinal approach or the use of retrospective questioning) as well as household and neighbourhood level factors in explanations of women's coping and adjustment, particularly those who had very few material resources and lived in poverty-stricken communities (Brandt, Dawes, & Bray, 2006).

3.2 THE STUDY

3.2.1 Overall research design

The research design chosen for the present study employed what Denzin (1989) terms 'between method' methodological triangulation, drawing on both a quantitative and qualitative research approach. The larger part of the study consisted of a cross-sectional, quantitative study conducted with 180 women living in the same community. In parallel, a

subset of five women who participated in the quantitative study were selected and followed up longitudinally[33] as case studies using qualitative methods.

The decision to employ methodological triangulation, and the choice of its component approaches, was deliberate and motivated by several factors (some of which have been referred to in section 2.9). The quantitative component allowed for the generation of quantifiable data regarding current psychological adjustment. This approach drew largely on previous research and theory and aimed at generalising to a broader population (other poor, HIV-infected women in South Africa in particular). While this kind of approach is important in establishing an evidence-base for policy-making, the qualitative component was employed to add depth to the understanding of HIV-infected women's psychological experiences. While this component of the study design allowed for a certain degree of verification of findings, this was not the primary aim. Rather the case studies aimed at complementing the quantitative study by addressing a level of understanding to which the quantitative, population-based approach did not lend itself. Given that the qualitative study was longitudinal in design, it also examined change over time in women's lives, something not possible in the cross-sectional study.

Finally, the choice of a triangulated approach allowed for the juxtaposition of statistical significance and the lived experience of mental health – substantial and complimentary perspectives in the context of policy decision-making. Further details and rationale regarding the research design are provided later in the chapter.

3.2.2 Site selection and description

For reasons beyond the control of the researcher, the main study could not be conducted in the same community as pilot work. Instead, the Klipfontein district (formerly the Nyanga health district) was chosen, covering mainly the suburbs of Crossroads, Phillipi, Gugulethu and Nyanga. This choice was based on the fact that the Crossroads Community Health Centre (CHC), where the study was based, was selected by the Western Cape Province's

[33] The initial research plan for the study involved conducting a longitudinal quantitative study as well. However, this was changed to a cross-sectional component given significant delays commencing recruitment as well as practical difficulties recruiting participants.

HIV/AIDS Directorate as the site with an existing public sector antiretroviral (ART) programme that the researcher could access (see Appendix A). The high levels of poverty and HIV prevalence in this area made it an appropriate option for the research.

According to the latest Census data for Crossroads (the suburb in which 50% of the women lived), 84% of individuals earn less than R1600 per month, while annual household income is less than R19 200 for 79% of households (City of Cape Town, 2006). While the Western Cape has the lowest provincial HIV prevalence rate in South Africa at 5% (Department of Health, 2006e), prevalence in the selected community is considerably higher. Figures for African women 15 to 49 years of age – the population relevant to the present study – have been reported at approximately 15% (Shisana et al., 2005). However, district level data for the chosen community indicated a prevalence of 29% (for Gugulethu/Nyanga), second only in the Western Cape to Khayelitsha (33%), and considerably higher than the national average (Shaikh & Abdullah, 2003). Also relevant with respect to the location of the site in the Western Cape is the fact that it has the highest public sector health expenditure per capita and the highest HAART coverage in South Africa (Nattrass, 2006a). While this places certain constraints on generalisability that will be discussed later, it also facilitates research with an infected population exposed to HAART which is not possible in many other parts of the country.

The chosen health centre was one of the larger ones on the Cape Flats and provided all basic public sector health services, including a baby and child health service, and a TB and HIV clinic. As part of the routine HIV service, patients received the standard treatment available through state heath services[34]. Further, in August 2004 (ten months before fieldwork began), the roll-out of HAART commenced in partnership with the UK-based non-governmental organisation (NGO), Absolute Return for Kids (ARK). During the period of the study (June 2005 to February 2006), the total number of patients on HAART at the CHC increased from 217 to 428 (Personal communication, Ms Meg Osler, Monitoring and Evaluation Coordinator, ARV programme, Provincial Government of the Western Cape, 5 September 2006). By March 2006, this figure had risen to 501, of which 353 (70%) were women.

[34] This comprises cortimoxazole prophylaxis; screening for and treatment of tuberculosis, STDs and other gynaecological problems; contraception and pregnancy testing; treatment of minor infections; and micronutrient supplementation (Department of Health, 2004).

Further, this was judged the most efficient approach to identifying a non-infected control group in the absence of HIV testing. Second, in order to balance out the skewed representation from the former method (where women all had at least one infant child), the remaining participants in this group were recruited through an independent research project conducted at the nearby Olunthu Community Centre in Gugulethu. As part of their participation in this project, all individuals had to be tested and their negative status had therefore also been confirmed not more than one week prior to recruitment into the present study. They were all adult women from neighbouring communities and therefore had similar socio-demographic profiles to women recruited elsewhere. The two groups did not differ significantly on the variables considered for matching (namely, age, education, income and partner status) and thus the data was pooled for all subsequent analyses.

Group 2, which consisted of HIV-infected women not on HAART, was recruited mainly but not exclusively through the HIV clinic at the Crossroads CHC. Initially, recruitment was conducted through two local service providers that worked with HIV-infected women, Yabonga (that had its container on the clinic premises) and Luvuyowethu, located in nearby Gugulethu. Approximately ten women were recruited through these organisations. However, given the bias toward women accessing psychosocial services (and therefore potentially better adjusted and different in a range of ways), the remaining recruitment was conducted through the clinic where women were not necessarily accessing any services other than routine medical care. In order not to compromise the ethics of the study, it was also necessary to stipulate that women in this group had a CD4 count of over 200. This was due to the fact that a CD4 count below 200 rendered women eligible for inclusion in the local HAART programme and therefore ineligible for inclusion in Group 2.

The remaining two study groups consisted of women on HAART, either those who had newly commenced treatment (Group 3) or those who had been on treatment for approximately six months (Group 4). Practical constraints played a role in the chosen time frame, given that there were few public sector HAART programmes with sufficient female patients on treatment for longer than six months. However, research evidence with HAART patients in South Africa also indicated that benefits to quality of life could accrue in this time and even begin to plateau out, thereby making this a justifiable period within which to examine women's psychosocial adjustment (Jelsma et al., 2005).

While Group 3 was defined as women that newly commenced treatment, in practice they were typically assessed at their clinic visit two weeks after commencement (for a routine pill count) since this facilitated contact with participants at the clinic without requiring an additional trip to the clinic for the purpose of the study alone. Participation in the HAART programme meant that women, at least those in Group 3, also had access to a patient advocate and most had been AIDS sick (i.e. classified as stage 4). Further, while there were no psychosocial exclusion criteria for the roll-out, active substance abuse, untreated active depression, non-disclosure of HIV status, and a lack of insight into the disease and its treatment were factors that could cause treatment to be delayed thereby reducing the likelihood that such women would be available for recruitment.

Overall criteria and sample size

Aside from the above-mentioned criteria, all participants had to be females of at least 18 years of age, and the primary caregiver of at least one child less than 18 years who lived in the woman's household. For the purpose of this study, the term primary caregiver was defined as the person *mainly responsible for the day-to-day care of a child*, including feeding, bathing, playing with, monitoring/supervising and transporting to or from activities. Consequently, the primary carer was not necessarily a child's biological mother, but rather the person taking on what is conventionally seen as the 'mothering' role. It is in this broader way that the term 'mother' is meant when used during the remainder of the dissertation, for reasons of brevity only.

It should also be noted that the specifiers of the child's age (less than 6 years) and HIV status (HIV negative) employed in pilot work were dropped in order to allow for the exploration of the impact of the child's HIV status and age on women's adjustment rather than controlling for it. Language and ethnic/racial group were not specifically sampled for. However, given the profile of the area, it was a more than reasonable expectation that the sample would almost homogenous with respect to both these criteria, namely black African and isiXhosa-speaking[35]. Further, women needed to have a reasonable expectation of living in the community for at least six months after the time of recruitment into the study

[35] According to census data for Crossroads, the area in which half the women lived, 95% of residents self-reported their home language as isiXhosa while 98.26% reported their ethnic group as Black African (City of Cape Town, 2006).

in the event that they were selected for follow-up. Finally, in order to ensure that the study represented the experiences of women in general, those directly involved in providing psychosocial services to PLWHA (e.g. peer educators, home-based carers and HIV/AIDS counsellors) were excluded from participation.

The target sample size was determined on the basis of a review of previous research as well as a power calculation in which infected and non-infected women were compared on both outcomes measures. With regard to anxiety, previous research was insufficient to derive an estimated effect size and thus Cohen's rule of thumb of 0.8 for a large effect size was employed (Howell, 1995). The calculation indicated that a sample size of 41 (per group) was required to support power of 0.9 for a two-tailed test at a significance level of 5%. With regard to depression, two calculations that drew on the published results of Johnson and Lobo (2001) and Tompkins et al. (1999) respectively indicated that a sample size of 26 to 38 would support power of 0.95 for a two-tailed test at a significance level of 5%. Since all of the aforementioned calculations were based on an insubstantial amount of prior research with different populations to the one in the present research, it was decided to elevate the target sample size per group to 50 women. Due to practical constraints, in particular the slow roll-out at the site, the eventual sample size for the two treatment groups was lowered to forty as opposed to fifty each.

Overall recruitment strategy

As far as possible, women in each group were consecutively recruited through the relevant service provider. For the two treatment groups (3 and 4), this meant recruiting all women identified as meeting the research criteria between the period June 2005 and February 2006 when the fieldwork was conducted. While not a random sample, the approach is less prejudicial to representativeness than self-selection through community organisations and service providers. However, it must also be noted that like any sampling through primary care providers, the sample may be biased against those that are severely ill given that they may not be able to attend the clinic at that time. Further, while the four groups were not explicitly matched, they were recruited through service providers in close proximity therefore making it likely that they lived in the same areas in which there was a high degree of comparability with respect to key socio-economic markers (all neighbouring

communities were extremely poor)[36]. The initial response rate to recruitment efforts was 100%. However, five women subsequently declined to participate or failed to complete the questionnaire and had to be replaced through sampling from the same population.

3.3 CROSS-SECTIONAL, QUANTITATIVE STUDY

3.3.1 Description of sample

Half of all participants lived in Crossroads while a further 25% lived in Philippi. The residence of most of the remaining participants was divided equally between Nyanga and Gugulethu, with three participants living further away, two in Khayelitsha and one in Mandalay. All except three participants (1.7%) were isiXhosa-speaking. The women ranged in age from 18 to 65 years, with an average age of 32 years (X=31.56, std dev=8.567). Nearly half of the women had between a grade 8 and grade 10 education (n=82, 45.8%), while 15% (n=27) had completed grade 12[37]. Five women (2.8%) had no formal education. Less than a third of the women were in paid employment (n=52, 28.9%), three (1.7%) were still scholars, two (1.1%) were retired and two (1.1%) were unable to work due to illness or disability. Fifty women (27.8%) did not have a partner at the time of the study and forty-one women (22.8%) had a partner who lived in the same household. Ninety percent (n=162) of the women were the biological mother of at least one child living in their household, while 18 (10%) only provided care for non-biological children.

Seventy-eight percent of the women (n=140) were not receiving a social grant, and only five (2.8%) received a disability grant[38]. Total individual income per month ranged from zero to R1 920, with a mean of just over R300 (X=R313.53, 95% C.I. R248.67–R378.38). Average monthly household income was just under R1 500 (X=R1 454.36, 95% C.I. R1 239.94–R1 668.78), but when five extreme values were removed (R5 680–R9 300), this amount fell to R1 288.94. Household size ranged from two to twelve members with an average of five (X=5.07, std dev=1.929). On average, children (under 18 years) constituted

[36] Two key variables on which groups could have been matched, namely, age and education, were included as control variables in the regression analyses to be reported in Chapter 4.
[37] South Africa's formal schooling system comprises 12 grades, of which grade 12 is the highest and last level. Grade 8 marks the beginning of secondary level schooling.
[38] Social grant is the local (South African) term for social assistance and public transfers (Booysen, 2004).

42% of each household. Only 17 households had an adult over the age of 60, and females tended to outnumber males to the ratio 3:2 (# females: X=3.08; # males: X=1.99).

On average, HIV-infected women (n=130) had been diagnosed 25 months or just over two years previously. The CD4 counts of HIV-infected women (n=130) ranged from 4 to 1 215, with only 11 women having a CD4 count over 500. The remaining women were divided almost equally between those with CD4 counts above and below 200. Classifying women based on their CD4 count, this meant that 8.9% of the HIV-infected women were asymptomatic (CD4 count>500), 47.6% were symptomatic (CD4 count 200-500) and 43.5% were AIDS-sick (CD4<200). Of those women on antiretroviral therapy, only five were not on one of the two first-line drug regimens as stipulated by the National and Provincial Departments of Health of South Africa, namely d4T (Stavudine), 3TC (Lamivudine) and Efavirenz or Nevirapine (Department of Health, 2004). These seven women were each taking one of the three second-line drugs, Didanosine (ddI), AZT (Zidovudine) and Lopinovir/ritonavir.

3.3.2 Data collection procedure and fieldwork management

Formal data collection for the cross-sectional, quantitative study was preceded by the recruitment of 180 women who met the above-mentioned eligibility criteria in each of the four groups. Each potential participant had the study and its objectives explained to her by one of the two fieldworkers, and gave written informed consent after receiving a copy of an information sheet translated into isiXhosa (see Appendices C/D and E/F respectively for the English and isiXhosa versions of these forms). A structured questionnaire was then administered to each woman at the premises of the relevant service provider. Wherever possible a private room or at least a relatively private space was used in order to ensure confidentiality. The approach of conducting interviews at the clinic or service provider was preferred over home visits since it involved no additional inconvenience to the participant (or expense to the researchers), and since issues of confidentiality were less complex than during home visits where people who did not know the women's serostatus might be present. Following completion of the questionnaire, and verification of the women's eligibility, medical data was also obtained by consulting participants' clinic files, to which they had given consent. Each woman was provided with R30's worth of food stamps for a

neighbouring retail store in order to acknowledge the time that they made available to participate in the study.

To assist with the collection of data for the quantitative study, two fieldworkers were appointed. Both were African women and both were middle-aged with experience in community work. One (H.N.) was a registered social auxiliary worker[39] with experience in the fields of mental health, women and HIV/AIDS, while the other (S.P.) had experience in research in poor communities, as well as being a local service provider for PLWHA. Both fieldworkers were trained in general research issues (including ethics), as well as being exposed to the specific objectives, methods and research tools of the present study. In-vivo training was conducted independently with both fieldworkers to ensure a sufficiently naturalistic, but technically sound approach to the interview context, particularly with respect to the administration of the standardised items in the questionnaire (to be described later). Ongoing training and input was also provided as issues emerged during the research process.

As part of the process of managing data collection, regular, usually weekly, meetings were held with both fieldworkers to discuss the recruitment and data collection process and to provide input on any difficulties experienced. Further, in between such meetings, each questionnaire was checked for omissions or inconsistencies in order that callbacks and follow-up could be conducted in parallel with data collection. This also allowed input required to ensure standardised administration of the questionnaire to be given during the course of the research.

3.3.3 Research tools

Table 3.2 presents the conceptual framework for the study variables which the below mentioned research tools were designed to explore. Further details are provided below.

[39] This is a qualification below the level of social worker in South Africa.

Table 3.2 Conceptual framework for study variables

Type of factor:	Individual level:	Household/network level:
Socio-demographic factors:	Age	Household composition
	Education	
	Employment	
	Partner status	
Poverty/income-related factors:	Personal socio-economic status	Household socio-economic status
Care-related factors:	Childcare roles	Childcare network
	Child characteristics	
	Other care roles	
HIV health-related factors:	Objective health markers	Objective health markers
	Treatment markers	Treatment markers
General health-related factors:	Objective health markers	Objective health markers
	Subjective health markers	
HIV non-health related factors:	Reason for testing	
	Time since diagnosis	
	Coping strategies	Coping of HIV+ partner/HH members
	Disclosure	Disclosure network
Psychological factors:	Mental health history	
	Social support	Social support network
	Coping strategies	

3.3.3.1 Questionnaire

A structured questionnaire was designed to cover the following areas of interest to the present study (see Appendix G):

- Socio-demographic and poverty-related information, including a household roster and details of household conditions;
- Caregiving information, including the roles played by women in relation to children and adults;
- General health information, including general medical history and perceptions of wellbeing, psychological history and household medical history;
- HIV-related health, including medical data for infected women, side-effects for those on HAART, and circumstances related to HIV testing and disclosure; and
- Current psychological adjustment and psychosocial factors associated with mental health, namely, coping strategies and social support.

The areas covered were selected based on the literature review presented in Chapter 2 and with the intention of situating women within the household context. Moreover, the conceptual framework facilitated the exploration of key poverty-, health- and mental health-related factors operating both at an individual level and a household or environmental level that could influence psychological adjustment either positively or negatively.

Sources consulted

While the questionnaire as a whole will not be described in further detail, a few points regarding definitions and sources must be mentioned. Several authoritative South African sources for questions on household and individual economics and circumstances were consulted. These were: the Census 2001 questionnaire (StatsSA, 2001), the Household Survey 2002 questionnaire (StatsSA, 2002b), the KwaZulu-Natal Income Dynamics Study (KIDS) 2004 questionnaire (StatsSA, 2002a), Booysen's (2004) Socio-Economic Impact on HIV Affected Households Study questionnaire, and the Cape Area Panel Study Household Module questionnaire (Social Survey Unit - Centre for Social Science Research, 2002a). These questionnaires represent the most substantive household-level surveys conducted in South Africa, including data periodically collected by government for the purpose of planning and resource allocation. In addition, Nattrass and colleagues' ARV Impact Study questionnaire was consulted as an example of a survey on HIV and HAART in progress in South Africa (Social Survey Unit - Centre for Social Science Research, 2002b).

For issues regarding how to operationalise and question around care tasks, and childcare in particular, Chobokoane and Budlender's (2001) work on the adaptation of the Time-use survey in South Africa and internationally was consulted. On the basis of both their suggestions and experience in the larger pilot study (see Swartz et al., 2005), appropriate categories of childcare were selected and applied in the questionnaire, including the more passive activity of supervision often omitted. This is also a point which the review of women's care roles in Chapter 1 highlighted (see section 1.2.2.3). The inclusion of this type of care facilitated the investigation of approaches to childcare more appropriate to contexts where communal caregiving is common and supervisory roles therefore important

(Bray & Brandt, 2005; Bray et al., in press). Finally, as already noted, several questions were modified or included specifically on the basis of observations and conclusions drawn from pilot work.

Definitions employed

With respect to definitions, the following must be noted. First, the definition of "household" as used in the South African census (2001) was employed, namely, that a household is a person or group of persons who live together at least four nights a week at the same address, eat together and share resources. Further, to be counted as living in a household, a person must spend at least four nights a week on average in the household. Second, the term "child" was used to refer to a person under the age of 18 years. While this definition is not universally applied, it is consistent with the definition used in South African legislation and policy, as well as key government surveys. Accordingly, it was decided to retain this definition for the present study. The use of the terms "primary caregiver" and "mother" have already been discussed (see section 3.2.3).

The use of standardised scales

Also included in the questionnaire were four standardised scales to assess current psychological adjustment (depression and anxiety) and factors associated with mental health (coping and social support). While issues of scientific and methodological rigour should ideally govern the choice of measures in such a dissertation, several constraints must be borne in mind: First, there are very few psychological measures that have been normed and standardised for use in South Africa; second, the levels of literacy and education in the research population are limited; and third, many women in the study were ill as well as having other constraints on time spent at the clinic. Consequently, measures were chosen on the basis that they could be either self-report or interviewer-administered, were relatively brief, required a low reading ability, and used relatively simple language and few response options (both of which help facilitate translation). Further, where no relevant instrument was available with local norms, preference was given to instruments that had at least been administered in South Africa so that comparative data was available

and/or the present study would contribute to a growing body of local evidence regarding the usefulness of the instrument in question.

One technical point regarding the administration of the four scales must also be mentioned. In order to accommodate the potentially unwieldy nature of response options and the fact that women were not necessarily equally or highly literate for verbal media, visual aids were employed. These consisted of A4 size boards (one for each scale) that provided a visual representation of each of the response options as well as the linguistic label in English and isiXhosa. This allowed fieldworkers to emphasise and clarify the role and meaning of these response options during the administration of the tool, as well as allowing participants to respond by pointing (rather than verbalising) and without necessarily having mastered the precise meaning of the linguistic label.

3.3.3.2 Brief COPE

Description

Women's coping strategies were assessed using the Brief COPE (Carver, 1997). It consists of 28-items and is an abridged version of the full COPE (Carver et al., 1989). The Brief COPE includes items on active coping, planning, positive reframing, acceptance, humor, religion, using emotional support, using instrumental support, self-distraction, denial, venting, substance use, behavioural disengagement and self-blame, with two items on each of the 14 subscales. Respondents indicated to what extent they made use of each coping response on a four-point Likert scale, ranging from 1 ("I haven't been doing this at all") to 4 ("I've been doing this a lot"). Higher scores indicate more frequent use of particular coping responses. Carver (1997) does not provide any clear directives regarding scoring. However, he states that second-order factors can be derived for a given sample and used as predictors (Carver, Meyer, & Antoni, 2000).

Previous use with HIV-infected populations

Only a few published studies were available using the Brief COPE, amongst them a study of the relationship between coping and functional quality of life in men and women living

with HIV/AIDS in the US (Vosvick et al., 2003). Two studies have been conducted with HIV-infected populations in South Africa, one of which was unpublished at the time of writing. Olley and colleagues used the Brief COPE to assess the coping responses of HIV-infected men and women attending an infectious diseases clinic in Cape Town (Olley, 2006; Olley et al., 2004a; Olley et al., 2004b; Olley et al., 2005), while Forsyth and colleagues (2005) examined the coping styles of poor, HIV-infected pregnant women. The latter study revised the Brief COPE to focus on HIV specifically and computed subscale scores for positive and negative coping. Olley et al., in contrast, reported data on the original 14 subscale scores as well as predictors based on a factor structure generated for their sample (details provided below). Two reviewed studies with HIV-infected recent mothers used the original COPE, one in the US (Smith et al., 2001) and one in Thailand (Bennetts et al., 1999).

Psychometric properties

Preliminary data on the psychometric properties of the Brief COPE were reported by Carver based on a longitudinal study on responses to Hurricane Andrew in the US (Carver, 1997). The study included a convenience sample of 168 adult residents of the affected community. Exploratory factor analysis confirmed that the factor structures of the Brief COPE and the original COPE were highly similar. In addition, internal reliability of the Brief COPE was reported to be good since alpha values for all subscales exceeded 0.50. Scores for 11 out of 14 subscales exceeded 0.60 and two exceeded 0.75 (religion α=.82, substance use α=.90). A more recent study also reported adequate reliability (α = .86) (Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002)[40]. Data on the psychometric properties of the Brief COPE are also available from two studies in South Africa. Forsyth and colleagues reported that the scale had good reliability, with Cronbach alphas (for their derived subscales) ranging from .60 to .70 (Personal communication, Maretha Visser, April 2005). In the other study, Olley et al. (2004b; 2005) reported a five factor structure, namely, active/planning, emotional venting, denial, social support and substance abuse.

[40] The authors do not specify whether this alpha value is for the total score on the scale and no statistics are provided from which to extrapolate this information.

In the present study, Factor Analysis was also used to derive a factor structure appropriate to the present sample that could be used as predictors of women's mental health outcomes (see Table 3.3 below). The combined factor model was adequate, accounting for 54% of the total variance. Further, all five extracted factors were well above the acceptable Eigen values, ranging from 1.68 to 5.82. The factors were named as follows: Active coping (instrumental and emotional support, active coping, positive reframing and planning), Avoidant coping (denial, self-blame and reducing efforts to cope), Religion/self-distraction (including acceptance), Substance use and Humour.

3.3.3.3 Centre for Epidemiologic Studies Depression Scale (CES-D)

Description

Women's levels of depression were measured using the Centre for Epidemiologic Studies Depression Scale (CES-D). The CES-D is a self-report instrument developed to measure current levels of depressive symptoms in the general population, and as a first-stage screening (as opposed to diagnostic) device in clinical and research settings (Measurement Excellence and Training Resource Information Center, 2002; Radloff, 1977; Radloff & Locke, 1986). The 20 items ask the person to rate the presence and frequency of symptoms experienced for the past week on a four-point scale ranging from "rarely or none of the time" (0) to "most or all of the time" (3). Total scores range from 0 to 60, with higher scores indicating higher levels of depressive symptoms. While factor analysis produced a four-factor structure for the CES-D (Depressive affect, Somatic symptoms and retarded activity, Positive affect, and Interpersonal relations), Radloff (1977) recommended the use of a total score only due to the scale's high internal consistency (details provided below).

Several studies employed a cut-off score to report the prevalence of individuals with probable depression. In Radloff's (1977) original study, a score of 16 was used as an arbitrary cut-off to compare the proportion of individuals in the general and clinical populations who scored at or above this point (21 and 70% respectively). More recent researchers have reported that a score of 16 resulted in a balance between false-positives and false-negatives when compared with research diagnostic criteria, and tended to detect

Table 3.3 Brief COPE rotated factor matrix[a]

Scale item	Factor				
	1	2	3	4	5
E15. I've been getting comfort and understanding from someone.	**.705**	-.069	-.041	.043	.133
E23. I've been trying to get advice or help from other people about what to do.	**.703**	.125	.210	-.078	.115
E7. I've been taking action to try to make the situation better.	**.621**	.142	.136	.045	.005
E17. I've been looking for something good in what is happening.	**.587**	-.057	-.063	.007	-.104
E5. I've been getting emotional support from others.	**.576**	.074	.153	-.127	.231
E21. I've been expressing my negative feelings.	**.568**	.340	-.473	.048	-.242
E10. I've been getting help and advice from other people.	**.547**	.068	.081	-.048	.168
E2. I've been concentrating my efforts on doing something about the situation I'm in.	**.538**	-.149	.001	.161	.010
E12. I've been trying to see it in a different light, to make it seem more positive.	**.529**	.146	.141	.052	-.068
E14. I've been trying to come up with a strategy about what to do.	**.508**	.112	.099	.095	.053
E25. I've been thinking hard about what steps to take.	**.468**	.103	.258	.060	-.035
E20. I've been accepting the reality of the fact that it has happened.	**.430**	.223	.046	.038	.148
E8. I've been refusing to believe that it has happened.	.207	**.697**	-.239	.066	.043
E3. I've been saying to myself "this isn't real".	.284	**.567**	-.215	.054	.059
E26. I've been blaming myself for things that happened.	-.036	**.562**	.095	.261	-.088
E6. I've been giving up trying to deal with it.	.048	**.491**	-.017	.083	.197
E9. I've been saying things to let my unpleasant feelings escape.	.432	**.470**	-.213	.084	.027
E13. I've been criticizing myself.	.083	**.421**	.038	.291	-.087
E16. I've been giving up the attempt to cope.	-.041	**.400**	.108	-.069	.114
E27. I've been praying or meditating.	.071	.179	**.665**	-.070	.002
E22. I've been trying to find comfort in my religion or spiritual beliefs.	.032	-.165	**.658**	-.246	-.112
E24. I've been learning to live with it.	.328	.139	**.481**	.102	.047
E19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	.241	-.208	**.480**	-.042	.180
E1. I've been turning to work or other activities to take my mind off things.	.136	-.130	**.359**	.088	.176
E4. I've been using alcohol or other drugs to make myself feel better.	.090	.173	-.106	**.934**	.081
E11. I've been using alcohol or other drugs to help me get through it.	.061	.197	-.068	**.921**	.040
E28. I've been making fun of the situation.	.108	.021	.082	.040	**.846**
E18. I've been making jokes about it.	.115	.281	.072	.039	**.741**

Extraction Method: Principal Axis Factoring
Rotation Method: Varimax with Kaiser Normalization
[a] Rotation converged in 7 iterations. Specified 5 factors to be extracted

major depression (although not minor depression or depressive personality) (Myers & Weissman, 1980). Others have, however, questioned the appropriateness of the cut-off score (see, for example, Kalichman, 1995; Schulberg et al., 1985). For example, US researchers suggested that while a score above 16 represented a "possible" case, a score of 23 or over could be used to designate "probable" cases (Husaini & Neff, 1980 in Radloff et al., 1986). In addition, a more recent review reported that a score of greater than or equal to 22 is indicative of probable major depression, while a score of 15 to 21 indicates mild to moderate depression, and a score of less than 15 indicates no depression (Measurement Excellence and Training Resource Information Center, 2002). Caution is recommended in the use of these cut-offs, particularly in the absence of normative data for a given population.

Previous use with HIV-infected populations

The CES-D is one of the most widely used self-report depression insruments and has been translated into several different languages and administered to a wide range of populations. It is commonly used in primary care practice (Schulberg et al., 1985; Thomas & Brantley, 2004). Thirteen of the reviewed studies on the psychological adjustment of HIV-infected women employed the CES-D, including three longitudinal studies (Milan et al., 2005; Miles et al., 2001; Richardson et al., 2001) and two conducted in developing country settings (Thailand and Uganda) (Bennetts et al., 1999; Kaharuza et al., 2006). In South Africa, two studies with HIV-infected populations have used the CES-D. As noted above, Forsyth and colleagues (2005) conducted research with poor, HIV-infected pregnant women, while Michaels (in progress) employed the CES-D to assess the mental health of caregivers of young children on HAART in Cape Town.

The use of the CES-D and other self-report measures of depression with HIV-infected populations has also been criticised by some who refer to the shared nature of symptoms of physical illness and somatic symptoms of depression (e.g. fatigue, diminished sleep and appetite, physical complaints and weight loss) and physical illness. The potential overlap between these symptoms renders the detection of depression in medically ill populations problematic, particularly with the use of self-report measures such as the CES-D (Drebing et al., 1994). Kalichman, Rompa and Cage (2000) reported that HIV symptoms loaded on

the same factor as somatic symptoms amongst PLWHA in the US, while Thomas and Bentley (2004) reported that somatic symptoms loaded on the same factor as depressive affect in low-income women in primary care settings. While the latter factor structure was not exactly replicated in the present sample, five out of seven somatic items loaded with depressive affect, as in Thomas and Bentley's sample. Although the CES-D is one of the measures of depression less influenced by symptoms of illness (Drebing et al., 1994), this is an important issue that will be examined further later in the dissertation (see Chapter 4, section 4.2.1.2).

Psychometric properties

Original psychometric data for the CES-D was derived from a pilot study conducted in households and psychiatric settings in Kansas City and Washington County (US) with a predominantly white population (Radloff, 1977). Norms for the original study indicated a mean score for the general population of 7.8–9.92 (Radloff et al., 1986), while 15-19% of a community-based sample score above the cut-off (of 16) used to define caseness. Amongst psychiatric inpatients, the latter figure was 70% (Radloff, 1977). A later small-scale clinical validity study with psychiatric inpatients reported an average score of 24, compared with the general population average of 9 (Radloff et al., 1986).

The CES-D demonstrated high internal consistency in both the general population (α=.85) and the psychiatric population (α=.90) (Radloff, 1977), a finding confirmed in several later studies (Hann, Winter, & Jacobsen, 1989; Lewinsohn, Seeley, Roberts, & Allen, 1997; Measurement Excellence and Training Resource Information Center, 2002; Myers et al., 1980). Two African studies also confirmed the internal consistency of the CES-D in their respective samples (Personal communication, Maretha Visser, April 2005; Kaharuza et al., 2006). Adequate test-retest reliability has also been established over intervals of between two and eight weeks (in the US) (r=.51-.69; Radloff, 1977).

The validity of the CES-D was established by patterns of correlations with other self-report measures (for example, the POMS-F, Hamilton's Clinical Rating Scale and Raskin Rating Scale; Hann et al., 1989; Radloff, 1977), by correlations with clinical ratings of depression (Radloff, 1977), and by relationships with other variables that supported its construct

validity. Discriminant and criterion-related validity was also reported to be adequate (ibid). The only African study to report on validity is Kaharuza et al's (2006) study with HIV-infected adults in Uganda. They found the construct validity of the CES-D to be adequate.

In the present study, a Cronbach's alpha of .786 was established, indicating good internal consistency.

3.3.3.4 Spielberger State Anxiety Inventory (STAI)

Description

The Spielberger State Anxiety Inventory (STAI) was employed to measure women's current levels of anxiety (Spielberger, 1983a). It was developed to assess how an individual feels "right now, at this moment" and focuses mainly on feelings of apprehension, tension, nervousness and worry experienced in a given situation. The 20 items ask the person to rate the intensity with which they experience certain feelings on a four-point scale, ranging from "not at all" (0) to "very much so" (4). Total scores range from 20 to 80, with higher scores indicating greater levels of current anxiety.

Previous use in HIV-infected populations

The Spielberger has been translated into more than thirty languages for cross-cultural research and clinical practice, and used with a range of populations (Spielberger & Diaz-Guerrero, 1976; 1983 in Spielberger, 1983a). It is the most widely used self-report measure of anxiety (Keedwell & Snaith, 1996). More recently, earlier studies with general medical patients have been extended to PLWHA (for example, Bertucci, 2000; Kalichman, Difonzo, Austin, Luke, & Rompa, 2002), including one of the reviewed studies on HIV-infected women (Catz et al., 2002). The STAI has been used in several studies in South Africa, including with submariners in the South African navy (van Wijk, 2001), alcoholics (Roberts, Emsley, Pienaar, & Stein, 1999; Spangenberg & Campbell, 1999), parents of children with Downs Syndrome (Spangenberg & Theron, 2001) and spouses of depressed patients (Spangenberg & Theron, 1999). However, no record of its use with PLWHA could be found and it has not been normed and standardised for use in South African populations.

The use of self-report anxiety inventories in PLWHA has not been widely criticised in the manner that depression instruments have. While there is also a potential overlap between anxiety symptoms and disease symptoms, the probability is less than with depression. Further, it is worth noting that the representation of somatic aspects of anxiety in the STAI, as opposed to arousal, mood, cognitive and behavioural aspects, is particularly low. One review noted that of the most frequently used self-rated scales of anxiety, the Spielberger was one of three that did not focus predominantly on somatic symptoms (Keedwell et al., 1996). Consequently, the STAI is a comparatively good choice for use with HIV-infected women.

Psychometric properties

The original normative samples for the STAI comprised working adults, college students, high school students and military recruits (while norms for the trait version are available for male neuropsychiatric patients, general medical and surgical patients, and young prisoners) (Spielberger, 1983a). This data indicates a norm of approximately 33 for women in the community sample, and 42 for general medical patients (administered the trait rather than state inventory). Extensive research has reported good psychometric properties for the STAI. Stability coefficients were relatively low in a sample of college and high school students (median .33), as expected for a measure sensitive to situational change, while alpha coefficients were high indicating good internal consistency (above .90 for working adults, students and military recruits) (Spielberger, 1983b).

The STAI has also shown good construct validity. Scores of military recruits undergoing stressful training were much higher than those for students tested under less stressful conditions, and levels of anxiety varied predictably with changes in the experimental condition (Spielberger, 1983a). Scores on the STAI were unrelated to scores on aptitude and achievement tests, demonstrating discriminant validity (ibid). Research with different ethnic groups in the US also confirmed the convergent and discriminant validity of the STAI through the examination of scores on scales such as the Beck Depression Inventory, the MMPI Depression and the Psychosocial Pain Inventory (Novy, Nelson, Goodwin, & Rowzee, 1993).

In the present study, the total anxiety score had adequate internal consistency (α=.710).

3.3.3.5 The Medical Outcome Study Social Support Survey - Revised

Description

The Medical Outcome Study Social Support Survey (MOS-SSS) was used to measure the social support of HIV-infected women (Sherbourne & Stewart, 1991). The MOS-SSS is a 19-item scale developed to assess various dimensions of functional social support received by persons with chronic conditions. In addition to a question that elicits information regarding network size, respondents rate how frequently they perceive tangible support, affectionate support, positive social interaction and emotional/informational support to be available when they need it on a 5-point Likert scale. Responses range from 1 ("None of the time") to 5 ("All of the time"), with higher scores indicating that support is more frequently available.

For the purpose of the present study, two additions were made to the scale. Firstly, an item regarding assistance with caregiving responsibilities ("Someone to help you take care of your children when you can't") was added in order to tap support related to child care which is a particular focus of this study (see Hough, Brumitt, Templin, Saltz, & Mood, 2003). Secondly, questions pertaining to satisfaction with the four types of social support assessed by the scale were included. The formulation of these questions was taken from the Social Support Questionnaire (Sarason, Levine, Basham, & Sarason, 1983). The rationale for this inclusion is that in addition to perceived support, satisfaction with support was hypothesised to be more predictive of women's physical and psychological wellbeing than network size and received support (Sarason et al., 1994). Respondents were asked to indicate their degree of satisfaction by choosing between a smiling and an unhappy face.

Previous use with HIV-infected populations

The MOS has been used in several health-related studies, including studies on PLWHA (see Tang, 2002; Vincent, 1997). The modified version of the MOS designed for the present study is currently being used in Michaels' (in progress) study referred to above in

order to assess the support experiences of caregivers of young children on HAART in Cape Town, South Africa.

Psychometric properties

Data for the development and validation of the MOS-SSS was drawn from a sample of 2 987 patients who participated in a larger study of health care systems in the US (Sherbourne et al., 1991). Based on this sample of ambulatory general medical patients, mean scores for total support, as well as tangible support, positive social interaction and emotional-informational support were 70 (out of 100), with affectionate support scoring slightly higher at 74. Results also confirmed that the MOS had good internal consistency (Cronbach alphas = .91-.97) and one-year test-retest reliability (stability coefficients = .72-.78) (ibid).

Although subscales were highly correlated in the original sample (r's = .69-.82), factor analyses supported the scoring of subscales as well as an overall index combining all 19 items (Sherbourne et al., 1991). Standardised factor loadings ranged from .76-.93 for tangible support, .86-.92 for affectionate support, .82-.92 for emotional/informational support and .91-.93 for positive social interaction. Evidence also supported the scale's convergent and discriminant validity (ibid). All items correlated highly with the hypothesised scales (r=.72 and greater) and all subscales correlated more highly with their own scale than with other social support scales.

Reliability analysis for the present study established that total scores and subscale scores, both those based on the original version of the scale and the revised one, had adequate reliability. Cronbach's alphas for total support and total satisfaction scores ranged from .83-.92, while subscale scores for availability of support ranged from .75-.86 and for satisfaction with support from .54-.81. Only satisfaction with affectionate support scored below .65, indicating moderate internal consistency.

3.3.4 Translation of instruments

The questionnaire, including the four standardised measures described, was translated from English into isiXhosa, the language either spoken at home or understood by all participants. Once the instruments had been translated, a back translation was conducted in order to determine the quality of the original translation and to identify difficulties which required further consultation. Consultation was then undertaken with a multilingual researcher experienced in issues of translation and cross-cultural validity, as well as obtaining substantial input from members of the local community. Local input was considered particularly important in order to attempt to capture the local language and manner of expression, as well as any issues that might be contextually specific and had not been anticipated by the researcher in the design of the instrument. This was in addition to refinements that were undertaken during the course of the study.

Finally, in order to facilitate the most effective possible use of the instruments, both the English and the isiXhosa text was included in the final questionnaire in order to allow fieldworkers to switch between the languages if required by the participant, without losing the clarity and preciseness of expression. This was particularly important with respect to the standardised scales where clarity of meaning and standardisation of use are especially important.

3.3.5 Data capture and analysis

Raw data from the questionnaires was captured in a Microsoft© Excel spreadsheet developed for the study. Capturing was completed with the help of a research assistant who was trained in the use of Excel and the project database. Further, practice sessions were held prior to the commencement of formal data capturing. A random subset of 10% of the questionnaires captured for each group was also checked for the purposes of further quality control. Following preliminary data cleaning in Excel, data was exported into the Statistical Package for the Social Sciences (SPSS) Version 14.0 where further data preparation was conducted. This involved standard data cleaning and checking procedures

as well as deriving variables required for analysis that were not created in the capturing of raw data.

Formal statistical analysis was preceded by appropriate exploratory analysis, both descriptive and bivariate. Descriptive analysis included computing means, standard deviations and measures of skewness for continuous variables, and generating frequency distributions for categorical variables. Bivariate analysis included correlational analyses and one-way analysis of variance (ANOVAs).

Given the research questions (as outlined in section 2.10), two main statistical procedures were appropriate for analysing the quantitative data.

First, ANOVAs and planned comparisons were used to compare group means and, second, multiple regression was conducted to determine the predictors of psychological adjustment. For some analyses, the outcome measures were dichotomised (and cut-off scores used). Although these analyses were used in a limited way and were not retained as part of the main analysis, the results are also presented in Chapter 4.

With regard to the second aim, to determine the predictors of adjustment, the research design would have permitted the use of path analysis rather than regression modeling. However, this approach was beyond the scope of the research objectives. The objective was not to produce a theoretical model of the pathways to adjustment in HIV-infected mothers, but rather to identify the important predictors of adjustment that accounted for the association between HIV status and psychological outcomes, should such an association be found. Moreover, given the limited previous research addressing this question in South Africa, the present research was partly exploratory and aimed at developing a sound empirical evidence-base on which to generate clear, but simple recommendations for policy and service provision. Path analysis is not required for this stage of such a research undertaking, but might be an important next step in taking the findings of the present study forward.

3.4 LONGITUDINAL, QUALITATIVE CASE STUDIES

3.4.1 Sampling strategy and description of sample

As already mentioned, in parallel with the quantitative study, a subset of five HIV-infected women was selected for follow-up as part of the longitudinal work. This number was chosen due to the fact that particularly rich data was able to emerge from a sample of the same size during pilot work. In addition, the focus of the qualitative study was to add depth to the understanding of women living with HIV and a larger sample size would have detracted from rather than contributed to this attempt.

Women were selected not on the basis of *a priori* criteria, but on the basis that preliminary analysis of questionnaires completed at the time indicated that these cases were extreme or unique, largely in one of two ways: these were women who were well adjusted despite particularly adverse circumstances (for example, multiple HIV-infected significant others or extreme poverty) or women who were poorly adjusted despite the presence of apparent protective factors (for example, a sound support system). Later analysis confirmed that these women represented the outliers or extremes in the sample on at least one variable (for example, the highest depression score, the highest CD4 count or the lowest rating of physical wellbeing).

At the time of their selection, two of the five women were on antiretroviral therapy, one who had recently commenced treatment and one who had been on treatment for just over six months. The remaining three women were not receiving HAART. However, one commenced treatment during the course of the study (further details are provided in Chapter 5). Two of the women were 28 years old, while the others were 31, 40 and 47 years of age. While one woman had no formal education at all, the others had completed between grade 7 and grade 11. Two were living off a disability grant, one was employed as a farmworker, another had two casual jobs as a domestic worker, and the other had no source of income or employment (at the time of recruitment). Except for one woman who had no children of her own (she cared for her niece and nephew who lived in the same household), the women had either one or two children, all of whom were resident with

them. One of these women also had two infant grandchildren that she largely cared for. One woman was married and another had a partner who lived in his own household. A more detailed picture of the individual women will be provided in Chapter 5.

3.4.2 Data collection procedure and fieldwork management

The women were engaged in in-depth interviews on three separate occasions - one, three and six months after their participation in the cross-sectional study. In the case of one of the participants, it was necessary for the fieldworker to conduct an informal home visit at a different time interval in lieu of the three-month follow-up due to the fact that the woman became seriously ill and required hospitalisation. Except for the one home visit, all interviews were conducted in a private room at the clinic and were tape recorded with the women's permission. Women were provided with transport money to cover the cost of making a special trip to the clinic for the interview, as well as being given food stamps to acknowledge their time. All interviews were conducted with the assistance of an interpreter (Z.C.) given that the women were all first language isiXhosa-speaking. However, during the first interview with one of the women, it emerged that she spoke good English and hence much of the interview was conducted without the use of the interpreter.

The interpreter was an isiXhosa-speaking graduate student in Psychology, with extensive research experience, including an interest in gender issues. As with other fieldworkers, she was familiarised with the background to the research as well as specific objectives, and was engaged in conversation throughout to further enhance the value of her contribution to the research process. Further, in order to maximise the quality of the interview transcripts, the same woman was employed to produce verbatim transcripts of the interviews in English and isiXhosa (see Appendix H for an example).

3.4.3 Research tools: Interview schedule

Although in-depth interviews were conducted that emphasise the exploration of material as it emerges in the interview, Mason's (2002) guidelines to conducting qualitative interviews were employed to develop an interview schedule. This was used as preparation rather than

a formal schedule to be followed during the interview. Consistent with Mason's approach, a "big research question", "mini research questions" and "interview topics related to mini research questions" were developed (see Appendix I for details).

The broad question or objective underpinning the three interviews conducted with each woman was to explore their personal story or experience of being an HIV-infected mother living in poverty. Further, given the concern with mental health, the interviews aimed to examine the role and relevance of psychological experience for these women in order to consider their lives through a psychological lens. Although the impact of women being interviewed previously about their HIV status (during the quantitative study) cannot be ignored, interviews were grounded in the assumption that HIV would not necessarily be a salient part of women's identities. Particularly during the first interview, the approach was therefore sensitive to allowing women to incorporate HIV into their narrative when and how they deemed it appropriate. The starting point for the interview was to have women talk about their life experience in general, beginning in childhood if possible, and to allow HIV related issues and/or psychologically-relevant experiences to unfold for further exploration. As part of applying a psychological lens, women's coping strategies, social support, and relationship lives and history was probed as details emerged.

Given the objective to use the longitudinal design to explore change, the second and third interviews were additionally concerned with questioning women about changes in their lives since the last interview and exploring the circumstances surrounding this change. After completion of the first round of interviews, given some of the perceived limitations posed by language barriers, it was decided to introduce the following two questions during the course of the interview as potentially useful prompts: "what are your main concerns at the moment?", and "what is your sense of the future?"[41]

For the final interview, in addition to developing the narrative (in many cases made possible by deepening rapport with the interviewees), women were invited to provide their opinion on one of the key issues that was emerging during the research process at the time, namely, whether HIV-infected women have special needs over and above non-infected women living in similarly impoverished communities. Women's opinions and rationale

[41] I am indebted to Dr Cathy Ward for this useful suggestion.

were elicited in response to this question, as well as the advice they would give government and those regulated to provide services to them.

3.4.4 Data analysis

Background theory and details regarding the approach to data analysis (narrative analysis) are included at the beginning of the analysis in Chapter 5 rather than within the present Methods chapter. Within the qualitative paradigm, the proximity of this material to the reporting of analysis is important and central to the development of a sound argument.

3.5 ETHICAL CONSIDERATIONS

Several measures, some of which have already been referred to, were taken in order to attempt to protect the integrity of the women participating in the study and to ensure that the research was conducted with appropriate attention to ethical principles. First, prior to the commencement of the research, both the methods and ethics of the protocol was approved by the University of Cape Town and permission was gained from the relevant health authority to conduct the research at the chosen site (see Appendices J and A respectively). Pilot work was approved by the Human Sciences Research Council's Ethics Committee.

Second, written informed consent was obtained from women for their participation in the study, including the audiotaping of interviews. Further, although women were identified through a service provider, the service provider made the first contact with women in order to verbally request study participation.

Third, with regard to maintaining confidentiality, and ensuring the anonymity of research participants, visits were conducted in a private room wherever possible and in a venue where it was highly likely that the participant's HIV status (whether negative or positive) was already known to those in the immediate surroundings. In addition, no identifying details were included on the questionnaire or any other study documentation that members of the research team had in their possession while conducting fieldwork.

Fourth, every attempt was made to understand, respect and maintain the integrity of the perspectives articulated by the women during the in-depth interviews, both while interviews were conducted and during data analysis. This is part of the ethical conduct of research, particularly within a qualitative paradigm.

Fifth, all fieldworkers had a background in mental health and/or service provision with HIV-infected women and were therefore in a position to conduct data collection with the required sensitivity. In addition, where indicated, women were referred to the nearest appropriate service provider, or provided with a brief session by the fieldworker herself for the purpose of containment.

Finally, women received a food voucher to acknowledge their contribution to the research process. Further, they will be invited to attend a feedback session at the conclusion of the research along with clinic staff and other roleplayers in the community, with due respect for the anonymity of those who choose to attend.

CHAPTER 4. RESULTS I: CROSS-SECTIONAL STUDY

This chapter presents the results of the cross-sectional study, organised as a response to the relevant research questions (1.1-4.2 as given in Chapter 2, section 2.10). Descriptive data for each of the independent and dependent study variables is presented first, followed by bivariate and multivariate analyses conducted, where relevant. Some additional discussion regarding the use of the two dependent variables as continuous rather than categorical, as well as the role of somatic items in measuring depression is also included in order to substantiate the approach to analysis taken in the present study.

4.1 DESCRIPTIVE DATA (SAMPLE CHARACTERISTICS)

Descriptive data is presented for a range of independent variables as well as the two dependent variables, namely, depression and anxiety. Some data has already been presented in brief as part of the description of the sample for the quantitative study (see section 3.4.1.2). In addition, data regarding the households in which the individual women live will be considered later to address the issues of representivity and generalisability (see section 6.3.1).

4.1.1 Independent variables

For reasons of brevity, those independent variables that are dichotomous will only be reported in the text as the frequency and percentage of 'yes' responses. Data on other categorical variables and continuous variables will be presented in greater detail.

4.1.1.1 Sociodemographic and poverty-related domain

First, several variables were computed that pertain to household conditions and socio-economic status. In general, these results are predictable given that women lived in a peri-urban community where levels of poverty were very high and access to essential amenities

and material possessions comparatively poor (see section 3.2.1). Most of these results are presented separately in Appendix K and some will be discussed further later (in section 4.1.4.1) as composite variables or types of deprivation that impact on psychological outcomes. One important variable to mention here, however, is that nearly two-thirds of the sample classified their household's income as irregular (see Table 4.1 below).

Table 4.1 Regularity of household income

	Frequency	Percent	Cumulative Percent
Very irregular	9	5.0	5.0
Irregular	114	63.3	68.3
Regular	8	4.4	72.8
Very regular	49	27.2	100.0
Total	180	100.0	

4.1.1.2 Care domain

Second, a group of variables was included to capture aspects of the participants' care roles. Again, some details are only included in the appendix (K).

Table 4.2 Number of household children for whom women is primary carer

	Frequency	Percent	Cumulative Percent
1	73	40.6	40.6
2	64	35.6	76.1
3	29	16.1	92.2
4	10	5.6	97.8
5	3	1.7	99.4
7	1	.6	100.0
Total	180	100.0	

Table 4.3 Number of childcare helpers for household children

	Frequency	Percent	Cumulative Percent
0	69	38.3	38.3
1	75	41.7	80.0
2	27	15.0	95.0
3	8	4.4	99.4
4	1	.6	100.0
Total	180	100.0	

Results show that women were the primary caregivers (not necessarily the biological mother) to between one and seven children, with just over 75% of women caring for either one (40.6%) or two (35.6%) children (see Table 4.2 above). Thirty-eight percent of these women had no childcare assistance, while just over 40% had one person to assist in caring for children living in the household (see Table 4.3 above).

In terms of the characteristics of the children for whom women were the primary carers, they ranged in age from newborns to children in their late teens. Further, large numbers of women cared for children in each age range, including under 6 year olds (68.3%), middle-school children (6-12 years: 54.4%) and adolescents (13-17 years: 44.4%). In addition to childcare within the household, a small number of women (2.2%) also provided childcare for children whose primary residence was in another household. Twelve women (6.7%) had the responsibility of providing for the special care needs of adults, including frail parents and physically disabled adults.

4.1.1.3 Health domain

Third, a group of general and HIV-specific health related variables was included.

Table 4.4 Perception of current physical health

	Statistic	Std. Error
Mean	7.30	.127
Std. Deviation	1.707	
Minimum	2	
Maximum	10	
Skewness	.006	.181
Kurtosis	-.443	.360

Table 4.5 Recent time in hospital (past 6 months)

	Frequency	Percent	Valid Percent	Cumulative Percent
None	149	82.8	82.8	82.8
<week	8	4.4	4.4	87.2
<month	17	9.4	9.4	96.7
1-3months	4	2.2	2.2	98.9
>3months	2	1.1	1.1	100.0
Total	180	100.0	100.0	

Across the sample as a whole, women rated their physical health (at the time of the study) as fairly good (M=7.30 on a scale from 1 to 10) (see Table 4.4 above). A small number of women (n=10, 5.6%) were receiving treatment for tuberculosis (TB) at the time of the study. However, a third (n=59, 32.8%) had received TB treatment at some point in the previous year. Twenty-six women (14.4%) had a chronic health problem other than HIV. The large majority had not been hospitalised at all in the previous six months, but just less than 10% (n=17, 9.4%) had spent up to one month in hospital and two women (1.1%) had been hospitalised for more than three months (see Table 4.5 above).

Results regarding the health of women's partners and household members showed that 27 women (15%) had at least one household member who was HIV-infected, while 57 women reported having a partner who was infected. The latter constitutes a third of women in the sample as a whole (31.7%), but nearly two-thirds of the women who were in a relationship at the time of the study (63.3%). Eight women (4.4%) had a partner receiving ARVs, while twelve women had either a partner or a household member on ARVs (6.7%).

4.1.1.4 Non-health HIV-related domain

Fourth, several non-health related issues specific to HIV were considered.

Table 4.6 Reason for HIV testing

	Frequency	Percent
Sickly/had OI	72	55.4
Child/ partner/ partner's girlfriend tested, sick or died	24	18.5
Pregnant	25	19.2
Voluntary	9	6.9
Total	130	100.0

Half of the women stated that their reason for having an HIV test was that they were ill, in many cases with an opportunistic infection (55.4%) (see Table 4.6 above). A further 18.5% tested because of the illness, death or HIV diagnosis of their child, partner or partner's girlfriend. Only nine women's (6.9%) reason for testing was entirely voluntary.

In terms of accessing HIV related support groups, just over 40% of the HIV-infected women were attending a group regularly, while seven women (5.4%) had a partner in a group. None of the women had a household member attending a support group.

Several issues related to the intentional disclosure of HIV status (as opposed to disclosure amongst medical professionals and by virtue of attendance of support groups) were considered. Only two women (1.5%) had not disclosed to at least one person. Of those who had disclosed, an average of three people were disclosed to a period of four and a half months after receiving a positive diagnosis (see Table 4.7 below).

Table 4.7 Number of disclosures and details of first disclosure

	# disclosures	Time until 1st disclosure (months)	Time since 1st disclosure (months)
Mean	3.43	4.53	18.79
Std. Deviation	1.698	11.190	20.385
Minimum	0	0	0
Maximum	9	66	122
Skewness	.594	3.423	2.082
Kurtosis	.343	12.916	6.031

Table 4.8 Disclosure network data

Domain	Category	Frequency (n=130)	Percent
Residence	HH member	108	83.1
	Non-HH member	114	87.7
	Live in neighbourhood	103	79.2
	Live in CT, outside neighbourhood	13	10.0
	Live outside CT	17	13.1
Relationship	Current partner	66	50.8
	Relative	123	94.6
	Close adult female relative*	95	73.1
	Mother	52	40.0
	Sister	71	54.6
	Son or daughter (any age)	43	33.1
	Friend	21	16.2
	Support group member	114	87.8
Sex	Female	118	90.8
	Male	90	69.2
Age	Child <18	38	29.2
	Child <11	9	7.3
	Girl <18	30	23.1
	Boy <18	14	10.8

*Close female relative was defined as a mother, sister or daughter.

Note: the category was coded "yes" if the respondent had disclosed to *at least one* person that met the criterion.

The large majority of women had disclosed their HIV status to at least one individual who lived in the same household (n=108, 83.3%), with relatively few disclosures being made outside of the women's neighbourhood (13 in another area in Cape Town [10%] and 17 outside of Cape Town [13.1%]) (see Table 4.8 above). Most women had also disclosed to at least one relative (n=123, 94.6%), most often their sister (n=71, 54.6%) or mother (n=52, 40%). Half the women had disclosed to a current partner (n=66, 50.8%). However, of those women who had a partner to whom they could disclose their HIV status (n=90), this figure was nearer three-quarters (73.3%). Disclosures were less likely to be made to men than women (n=90, 69.2% versus n=118, 90.8%). Just less than a third of women disclosed to a child (n=38, 29.3%), with the majority of these children being over the age of 11 and female (n=30 girls and n=14 boys).

4.1.1.5 Psychological domain

Finally, three categories of psychological variables were included. Results relevant to mental health history are summarised in Table 4.9 below. They show that only twenty participants (11%) reported experiencing a psychological problem at some point in their past, with three women never having received treatment. Further, only three of the 18 HIV-infected mothers who reported a problem experienced this prior to their positive diagnosis. Sixteen reported accessing psychological treatment after being diagnosed HIV positive and of the thirteen women who received counselling, eleven explicitly mentioned that counselling was sought due to difficulty accepting their diagnosis. (See table on next page.)

Table 4.9 Summary data on mental health history

Group		Type of problem	Time of problem	Time of treatment			Type of treatment		
			Psych problem premorbid*	Untreated psych problem	Psych treatment premorbid	Psych treatment post-HIV	Counsel-ling	Hospita-lised	Western medication	Sangoma/ traditional medication
1	HIV-	Depressed, worried about daughter's problem behaviour.	yes	no	yes	N/A	no	no	yes	no
		Experienced emotional abuse as a child, attempted suicide at 15, and having relationship problems as an adult.	yes	yes	N/A	N/A	no	no	no	no
2	HIV+	Feeling depressed; difficulty sleeping, low energy, and everything an effort.	no	no	no	yes	yes	no	yes	no
		Depression (was raped twice)	yes	no	yes	yes	yes	no	no	no
		Depression	no	no	no	yes	yes	no	no	no
		Depressed, very confused and disappointed when diagnosed as newly married to husband.	no	no	no	yes	yes	no	no	no
		Difficulty accepting positive diagnosis.	no	no	no	yes	yes	no	no	no
		Depression	yes	no	yes	yes	no	yes	yes	no
		Minor stroke led to testing positive for HIV and needed counseling and medication to deal with this.	no	no	no	yes	yes	no	yes	no
3	New HAART	Feels stressed a lot and has difficulty sleeping at night.	no	no	no	yes	yes	no	no	no
		Confused, difficulty accepting status.	no	no	no	yes	yes	no	no	no
		No self-report, but clinic staff advised that receives regular psychiatric treatment and needs supervision.	yes	no	yes	yes	no	no	yes	no
		Difficult time trying to accept after tested positive.	no	no	no	yes	yes	no	no	no
		Still battling with being HIV positive.	no	no	no	yes	yes	no	no	no
		Thoughts of death on diagnosis; needed help accepting.	no	no	no	yes	yes	no	no	no
		Difficulty accepting positive diagnosis.	no	no	no	yes	yes	no	no	no
4	6mo HAART	Alone and depressed when partner left after hearing my status. Sisters-in-law accused of infecting her partner.	no	no	no	yes	yes	no	no	no
		Was admitted to psychiatric hospital for TB of brain.	no	no	no	yes	no	yes	no	no
		Felt like water in head and lay awake at night thinking.	no	yes	N/A	N/A	no	no	no	no
		Sometimes feel depressed.	no	yes	N/A	N/A	no	no	no	no
		n=20	**n=5**	**n=3**	**n=4**	**n=16**	**n=13**	**n=2**	**n=5**	**n=0**

* In the case of an HIV positive mother, premorbid means prior to the HIV diagnosis. For the control group, it simply refers to any time prior to assessment for the study.

Coping strategies and social support were also assessed as part of the psychological domain. With respect to social support, three aspects were considered: the size of women's support networks, the perceived availability of support and women's satisfaction with support received. (For ease of interpretation, only standardised scores for availability and satisfaction have been provided. See Appendix K for a summary of raw scores.)

Table 4.10 Support network size

	Frequency	Percent	Cumulative Percent
0	2	1.1	1.1
1	94	52.2	53.3
2	57	31.7	85.0
3	18	10.0	95.0
4	6	3.3	98.3
5	1	.6	98.9
6	2	1.1	100.0
Total	180	100.0	

Table 4.11 Social support network data

Domain	Category	Frequency (n=178)	Percent
Residence	HH member	93	52.2
	Non-HH member	178	100
	Live in neighbourhood	106	59.6
	Live in CT, outside neighbourhood	14	7.9
	Live outside CT	16	9.0
Relationship	Current partner	36	22.2
	Close female relative*	110	61.8
	Mother	42	23.6
	Sister	66	37.1
	Son or daughter (any age)	16	9.0
	Friend	39	21.9
Sex	Female	165	92.7
	Male	55	30.9
Age	Child <18	6	3.4
	Child <11	0	0
	Girl <18	6	3.4
	Boy <18	0	0

*Close female relative was defined as a mother, sister or daughter.

Table 4.12 Perceived availability of social support (standardised scores)

	Total	Tangible support	Affectionate support	Positive social interaction	Emotional/ informational support
Mean	80.48	80.49	84.26	75.25	81.67
Std. Deviation	11.41	13.75	14.88	17.03	12.09
Minimum	36	40	20	20	32.50
Maximum	100	100	100	100	100.00
Skewness	-.61	-.63	-1.10	-.44	-.60
Kurtosis	1.10	.26	1.50	-.47	1.24

Table 4.13 Satisfaction with social support (standardised scores)

	Total	Tangible support	Affectionate support	Positive social interaction	Emotional/ informational support
Mean	93.25	93.89	95.19	85.28	96.11
Std. Deviation	12.07	16.11	15.41	25.04	12.62
Minimum	10	0	0	0	12.50
Maximum	100	100	100	100	100.00
Skewness	-3.68	-3.41	-3.60	-1.57	-4.54
Kurtosis	19.42	12.98	13.76	1.38	23.86

Two women (1.1%) reported having no close friends or relatives who they could count on for support and, on the whole, support networks were small (see Table 4.10 above). The large majority (83.9%) of women reported having either one or two support network members (n=94, 52.2% and n=57, 31.7% respectively). The largest support network comprised six members. All women received support from at least one person who lived outside of the household (see Table 4.11 above). Women were most likely to receive support from a sister (n=66, 37.1%), followed by mothers (n=42, 23.6%) and friends (n= 39, 21.9%). Only a third of women received support from a male (n=55, 30.9%). Six children (3.4%), all of them adolescent girls, constituted part of a women's support network.

Across the sample as a whole, perceived availability of support as well as satisfaction with support was reported to be very high (see Tables 4.12 and 4.13 respectively). This finding held both for overall support and satisfaction, and different types of support. Although still very high, the least available type of support was positive social interaction. Satisfaction with this type of support was also lowest.

With respect to coping strategies employed in times of stress, the results presented below (in Table 4.14) show that religion and self-distraction was used most frequently followed by active forms of coping (such as instrumental and emotional support, positive reframing and planning). The women reported that they infrequently used drugs or alcohol to cope.

Table 4.14 Coping strategies: standardised scores

	Active coping	Avoidant coping	Religion & self-distraction	Substance use	Humour
Mean	77.91	34.56	82.94	28.96	38.82
Std. Deviation	10.43	11.40	12.75	13.11	15.32
Minimum	50.00	25.00	40.00	25.00	25.00
Maximum	100.00	75.00	100.00	100.00	100.00
Skewness	.18	1.57	-.87	3.89	.83
Kurtosis	-.56	2.22	.65	15.80	.38

4.1.2 Dependent variables

Summary descriptive data for the two dependent variables is presented below (see Table 4.15). This shows that depression scores for the sample as a whole had a mean of 11.72 and a standard deviation of 8.060 out of a potential range of 0 to 60, with higher scores reflecting more symptoms of depression. Out of a possible range of 0 to 80, anxiety scores for the sample had a mean of 31.41 and a standard deviation of 6.665. Further, both distributions were positively skewed. Descriptive data disaggregated according to HIV status are also provided below.

Table 4.15 Descriptive data: Total depression and Total anxiety

	Total depression			Total anxiety		
	HIV+	HIV-	Combined	HIV+	HIV-	Combined
Mean	13.38	7.40	11.72	32.43	28.76	31.41
Std. Deviation	7.47	8.00	8.06	6.04	7.50	6.67
Minimum	1	0	0	20	20	20
Maximum	39	41	41	57	59	59
Skewness	1.29	2.60	1.32	1.83	1.95	1.56
Kurtosis	1.71	7.73	1.93	4.96	5.01	3.94

4.2 THE IMPACT OF HIV STATUS AND DISEASE SEVERITY ON PSYCHOLOGICAL ADJUSTMENT

The first part of the analysis addressed the impact of HIV status and disease severity on the psychological adjustment of mothers. The analysis comprised two sub-sections. One investigated whether HIV positive mothers exhibited poorer psychological adjustment than HIV negative mothers (research question 1.1). The other section investigated whether or not there was a difference in the psychological adjustment of asymptomatic, symptomatic and AIDS-sick HIV positive mothers, and whether they differed from HIV negative mothers (research question 1.2).

4.2.1 Preliminary considerations

Comparisons between various combinations of groups were required to address research questions 1.1, 1.2 and 2.1-2.4. Prior to the presentation of these results, however, two important issues must be discussed, namely, the potential impact of somatic items on the use of the depression inventory and the treatment of outcome measures as either continuous or categorical.

4.2.1.1 Outcomes as continuous versus categorical variables

The treatment of depression and anxiety as categorical variables is consistent with an epidemiological approach that seeks to establish the prevalence of mental disorders based on whether or not individuals meet relevant case criteria. When adopting this approach using self-report instruments, a cut-off score is employed to determine whether or not someone can be classified as a "case". This is in contrast with the use of scores in a continuous manner to identify levels of distress or symptomatology.

It was decided that the appropriate approach for the present study was to treat both outcome measures (depression and anxiety) as continuous, the main reason being that cut-offs for the relevant context and population had not been empirically derived and validated. Further, this approach is adequate given that the research questions seek to establish

statistical difference between sub-groups rather than reporting prevalence. While measures such as the CES-D have been used to report prevalence, (as stated in Chapter 3) the CES-D was developed as a screening instrument to identify probable cases for further investigation rather than as an instrument suited to the objectives of an epidemiological enquiry (Radloff, 1977).

While the continuous approach is therefore adopted throughout the analysis, this section briefly reports the results of an analysis employing depression as a categorical variable in order to facilitate comparison with some of the international literature (Kalichman, Rompa, & Cage, 2000). In addition, some of the very limited research currently available in South Africa has employed an epidemiological approach. Such comparisons should, however, be made with caution.

For the purpose of this analysis, two cut-off scores as suggested by Kalichman and colleagues are employed (Kalichman et al., 2000). First, a clinical cut-off of 16 was applied which has been suggested to demonstrate acceptable sensitivity and specificity for possible depression. Second, a score of 23 or greater preferred by others, including in medically ill populations, was also applied for comparative purposes (ibid; Thomas et al., 2004). The results of the crosstabulations and Chi-square test are presented below (see Tables 4.16 and 4.17 respectively):

Table 4.16 Crosstabulations: Group x Depression

Total depression score			≥ 16	≥ 23
Group	HIV-	Count	5	3
		% within Group	10.0%	6.0%
		% within Depression	11.6%	15.8%
	HIV+ (no HAART)	Count	19	10
		% within Group	38.0%	20.0%
		% within Depression	44.2%	52.6%
	New HAART	Count	13	3
		% within Group	32.5%	7.5%
		% within Depression	30.2%	15.8%
	6mo HAART	Count	6	3
		% within Group	15.0%	7.5%
		% within Depression	14.0%	15.8%
	All HIV+	Count	38	16
		% within Group	29.2%	12.3%
		% within Depression	88.4%	84.2%
Total		Count	43	19
		% within Group	23.9%	10.6%
		% within Depression	100.0%	100.0%

Table 4.17 Chi-square statistics: Prevalence of depression x Group

	Group	Cut-off of 16	Cut-off of 23
Chi Square [a, b]	2.222	49.089	112.022
df	3	1	1
Asymp. Sig.	.528	**.000**	**.000**

[a] 0 cells (0%) have expected frequencies less than 5. The minimum expected cell frequency is 45.0.
[b] 0 cells (0%) have expected frequencies less than 5. The minimum expected cell frequency is 90.0.

The results showed a significant difference across groups for levels of depression, with nearly half of depressed individuals falling in the group of HIV-infected women without access to HAART, regardless of the cut-off employed. Using the lower cut-off of 16, the overall prevalence of depression in the sample is 23.9%. Thirty-eight percent of HIV-infected women not on HAART were depressed, followed by 32.5% of those newly on HAART, 15% of those on HAART for six months and 10% of seronegative women in the control group. The use of the more conservative cut-off of 23 reflects a similar pattern, but predictably with lower prevalence rates. The overall prevalence falls to 10.6%, with the highest prevalence amongst HIV-infected women not on HAART at 20%. Six percent of seronegative women were depressed, while 7.5% of women in each of the treatment groups were depressed.

4.2.1.2 Impact of somatic items on depression scores[42]

The second consideration relates to the criticism of self-report measures of depression such as the CES-D referred to in section 3.4.2.1. Kalichman (1995) argues that the overlap between disease symptoms and somatic symptoms of depression potentially confound estimates of depression in HIV-infected (as well as other medically ill) populations and inappropriately elevate prevalence rates. While specific disease symptoms were not elicited in the present sample, the correlation between levels of depressive symptoms and women's reported perception of their physical health was explored in order to consider the relevance of this claim for the present study.

Table 4.18 Pearson's correlations: Depression x Perception of physical health

		Perception of physical health	Depression (with somatic items)
Depression (with somatic items)	Pearson Correlation	-.388(**)	
	Sig. (2-tailed)	.000	
	N	180	
Depression (excl. somatic items)	Pearson Correlation	-.456(**)	.969(**)
	Sig. (2-tailed)	.015	.000
	N	180	180

** Correlation is significant at the 0.01 level (2-tailed).

Results showed that perceptions of physical health were significantly associated with depression scores, although the size of the correlation indicates that several other variables contributed to this relationship (see Table 4.18 above). Nonetheless, poorer perceptions of physical health were significantly associated with higher levels of depressive symptoms, both in the presence and absence of somatic symptoms of depression. While the correlation was marginally greater when somatic items were excluded, the fact that a significant correlation exists suggests that somatic symptoms might contribute to false positives in the identification of above-threshold cases.

One methodological remedy offered by Kalichman (1995) to address this concern is to omit overlapping items. Although this approach is typically applied in the context of

[42] The reasons why this consideration was not taken into account with regard to anxiety scores has already been discussed in Chapter 3 (see section 3.3.3.4).

estimating prevalence rather than comparing groups, it was adopted in the present study in an attempt to be as rigorous as possible. Further, here the impact on prevalence is reported for the purpose of comparison. While there is not a standardised cognitive-affective depression subscale for the CES-D, and not all studies appear to have removed the same items in applying this approach (see, for example, Burrack et al., 1993 in Kalichman, 1995; Ickovics et al., 2001; Kaharuza et al., 2006; Kalichman et al., 2000; Milan et al., 2005; Schrimshaw, 2002; Siegel et al., 1998), for the present study, items 2, 5, 7, 11 and 20 that might reflect either depression or illness or medication use were excluded (i.e. restless sleep, poor appetite, fatigue, lack of energy and poor concentration). This decision was taken based on the fact that the majority of studies removed five (as opposed to six or seven) items, and the most recent researcher to employ this strategy confirmed that these were the five items that she and her colleagues removed (Personal communication, Assistant Professor Stephanie Milan, 25 October 2006; see also Ickovics et al. (2001) for an earlier report). This is also the only published study to employ this strategy with the CES-D as part of a longitudinal research with HIV-infected women. In order to determine an appropriate cut-off for the reduced scale, the criteria suggested by Radloff and Locke (1986) were employed, namely, the cut-off is that score that identifies the upper 20% of the distribution[43]. For the present sample, the appropriate cut-off is a score of 10.

The results of the crosstabulations and Chi-square analysis are presented below (see Tables 4.19 and 4.20 respectively):

[43] Several studies do not employ a revised cut-off score when excluding somatic items (for example, see Milan et al., 2005; Simoni et al., 2000d). Another method used by some researchers is to weight the scores in order to retain the range of the original CES-D from 0 to 60 as well as the typical cut-off score (see, for example, Schrimshaw, 2002).

Table 4.19 Crosstabulations: Group x Depression (excl. somatic items)

Excluding somatic items			≥ 10
Group	HIV-	Count	7
		% within Group no	14.0%
		% within Depression	11.5%
	HIV+ (no HAART)	Count	25
		% within Group no	50.0%
		% within Depression	41.0%
	New HAART	Count	18
		% within Group no	45.0%
		% within Depression	29.5%
	6mo HAART	Count	11
		% within Group no	27.5%
		% within Depression	18.0%
	All HIV+	Count	54
		% within Group no	41.5%
		% within Depression	88.5%
Total		Count	61
		% within Group no	33.9%
		% within Depression	100.0%

Table 4.20 Chi-square statistics: Prevalence of depression (excl. somatic items) x Group

	Group	No somatic items (cut-off of 10)
Chi Square [a, b]	2.222	18.689
Df	3	1
Asymp. Sig.	.528	**.000**

The results indicated higher levels of depression, both overall and within the respective groups, than produced using the full scale and cut-off of 16. This suggests that within the study population, affective symptoms made a substantial contribution to self-reported depression. This finding will be considered further later (in Chapter 6) along with subsequent analyses comparing the impact of somatic items.

4.2.2 Bivariate analysis

Given the argument presented above, from this section onwards, only analyses treating outcome measures as continuous variables are reported. Consequently, in order to address

research questions 1.1, 1.2 and 2.1-2.4, two one-way ANOVAs (analysis of variance) and a series of planned comparisons were conducted. Prior to formal data analysis, the sample data was also checked for violation of assumptions.

4.2.2.1 HIV status

Research question 1.1 addressed whether or not HIV positive mothers exhibited poorer psychological adjustment than HIV negative mothers. Results of the tests of normality and homogeneity of variance revealed that while variances across the groups were sufficiently homogenous, not all the poulations from which the groups were sampled were normally distributed (see Tables 4.21 and 4.22 below).

Table 4.21 Tests of Normality

Dependent variable	Grouping variable	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
		Statistic	df	Sig.	Statistic	df	Sig.
Total depression	HIV-	.249	50	**.000**	.706	50	**.000**
	HIV+ (no HAART)	.154	50	**.005**	.927	50	**.004**
	New HAART	.157	40	.014	.884	40	**.001**
	6mo HAART	.160	40	.011	.835	40	**.000**
Total anxiety	HIV-	.174	50	**.001**	.829	50	**.000**
	HIV+	.200	50	**.000**	.854	50	**.000**
	New HAART	.181	40	**.002**	.889	40	**.001**
	6mo HAART	.235	40	**.000**	.720	40	**.000**

[a] Lilliefors Significance Correction

Table 4.22 Test of Homogeneity of Variances

	Levene Statistic	df1	df2	Sig.
Total depression	1.365	3	176	.255
Total anxiety	1.103	3	176	.349

While this may suggest that the assumptions for the use of the ANOVA and parametric tests in general have been violated, the ANOVA is robust with respect to violations of assumptions under certain conditions. According to Howell (1995), in practice, if the populations are similar in distribution and if the largest variance is no more than four times the smallest, the ANOVA is likely to be valid. Consequently, since all four populations were similarly distributed (positively skewed) and the largest variance was not more than

four times the smallest variance, it was possible to proceed with analysis of variance (see Tables 4.23 and 4.24 below for measures of skewness and variance). (For comparative purposes only, non-parametric tests were also performed and are reported in Appendix L. Only one group difference was noted that will be mentioned where relevant.)

Table 4.23 Descriptive data: Total depression x Group

	HIV-	HIV+ (no HAART)	New HAART	6mo HAART
Mean	7.40	14.72	13.80	11.30
Variance	63.96	67.80	43.96	48.57
Std. Deviation	8.00	8.23	6.63	6.97
Minimum	0	2	4	1
Maximum	41	38	36	39
Skewness	2.60	.89	1.51	2.00
Kurtosis	7.73	.22	3.06	5.86

Table 4.24 Descriptive data: Total anxiety x Group

	HIV-	HIV+ (no HAART)	New HAART	6mo HAART
Mean	28.76	32.40	33.30	31.60
Variance	56.31	39.51	31.40	38.14
Std. Deviation	7.50	6.29	5.60	6.18
Minimum	20	20	23	23
Maximum	59	54	54	57
Skewness	1.95	1.60	1.49	2.69
Kurtosis	5.01	4.32	4.02	9.15

While the results of the linear contrasts rather than the overall significance of the model are relevant to research questions 1 and 2.1-2.4, for completeness, this result is also presented below (in Table 4.25). The overall models for both depression and anxiety were significant at the 5% level[44].

[44] Throughout this dissertation, the significance of results is tested at the 5% level. Further, p-values that are significant at this level are highlighted in boldface in the summary SPSS tables.

Table 4.25 ANOVA: Total depression and Total anxiety

Variable		Sum of squares	df	Mean square	F	Sig.
Total depression	Between Groups	1563.231	3	521.077	9.112	.000
	Within Groups	10064.880	176	57.187		
	Total	11628.111	179			
Total anxiety	Between Groups	544.458	3	181.486	4.312	.006
	Within Groups	7407.120	176	42.086		
	Total	7951.578	179			

To address research question 1.1, a linear contrast was created comparing the combined mean for the three groups of HIV-infected mothers with the mean for the control group across both dependent variables (see Table 4.26 below).

Table 4.26 Contrast tests

Dependent variable	Value of Contrast	Std. Error	t	df	Sig. (2-tailed)
Total depression	-17.62	3.896	-4.522	81.990	.000
Total anxiety	-11.02	3.559	-3.097	74.653	.003

The results show that HIV positive mothers exhibited a significantly higher number of symptoms of depression and anxiety than HIV negative mothers living in the same community. The impact of reducing depression to an assessment of cognitive-affective symptoms, and excluding somatic ones, is summarised in Appendix L. For the question at hand, the findings remained unchanged.

4.2.2.2 Disease severity

Research question 1.2 addressed whether or not there was a difference in the psychological adjustment of asymptomatic, symptomatic and AIDS-sick HIV positive mothers, and whether they differed from HIV negative mothers. Results of the tests of normality and homogeneity of variance revealed only a marginal violation of homogeneity for the anxiety data (see Table 4.28 below). However, the distributions in three of the four groups were significantly non-normal (see Table 4.27 below). Examining the variances, the largest variance for the anxiety data was also more than ten times the smallest variance (most likely as a result of the small sample size for this group) (see Table 4.29 below). Based on

Howell's (1995) approach described above, non-parametric tests were therefore employed to analyse the anxiety data, while parametric tests were appropriate for the depression data. (Both parametric and non-parametric results for each variable are reported in Appendix L.)

Table 4.27 Tests of Normality

Outcome variable	Grouping variable	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
		Statistic	df	Sig.	Statistic	df	Sig.
Total depression	HIV-	.249	50	**.000**	.706	50	**.000**
	Asymptomatic	.214	11	.168	.876	11	.093
	Symptomatic	.191	59	**.000**	.861	59	**.000**
	AIDS-sick	.151	54	**.004**	.927	54	**.003**
Total anxiety	HIV-	.174	50	**.001**	.829	50	**.000**
	Asymptomatic	.255	11	.044	.881	11	.108
	Symptomatic	.206	59	**.000**	.840	59	**.000**
	AIDS-sick	.180	54	**.000**	.850	54	**.000**

[a] Lilliefors Significance Correction

Table 4.28 Test of Homogeneity of Variances

	Levene Statistic	df1	df2	Sig.
Total depression	1.363	3	170	.256
Total anxiety	2.679	3	170	**.049**

Table 4.29 Descriptives: Total depression x Disease severity

	HIV-	Asymptomatic	Symptomatic	AIDS
Mean	7.40	13.64	13.92	13.13
Variance	63.96	69.06	73.80	34.19
Std. Deviation	8.00	8.31	8.59	5.85
Minimum	0	5	2	4
Maximum	41	31	39	32
Skewness	2.60	1.137	1.38	1.07
Kurtosis	7.73	.424	1.46	1.31

Table 4.30 Descriptives: Total anxiety x Disease severity

	HIV-	Asymptomatic	Symptomatic	AIDS
Mean	28.76	31.36	32.36	32.91
Variance	56.31	5.26	51.54	29.75
Std. Deviation	7.50	2.29	7.18	5.45
Minimum	20	26	20	23
Maximum	59	35	57	54
Skewness	1.95	-.91	1.69	1.84
Kurtosis	5.01	2.84	3.51	5.52

First, the role of access to treatment per se and the duration of treatment was analysed (research questions 2.1-2.4). This comprised whether or not commencing HAART was associated with improved psychological adjustment (2.1); whether there was an improvement in adjustment from the time that mothers commenced HAART to six months on HAART (2.2); and whether the adjustment of mothers on HAART for six months was better than the adjustment of mothers without access to HAART (2.3) and HIV negative mothers in the same community (2.4).

Second, the analysis addressed whether psychological adjustment was predicted by changes in health (either perceived or actual) while on HAART (research question 2.5).

4.3.1 Bivariate analysis

As stated in the previous section, linear contrasts were used to address research questions 2.1-2.4. This approach was preferred to one-way ANOVA post-hoc procedures since only specified comparisons needed to be made. In addition, this approach is both more parsimonious and statistically sound in that it reduces the type I error rate associated with running multiple tests. The results of these contrast tests for each research question are presented below (see Tables 4.35-4.38):

Contrast Tests:

Table 4.35 Planned comparison: Question 2.1

Dependent variable	Value of Contrast	t	df	Sig. (2-tailed)
Total depression	.92	.587	87.993	.559
Total anxiety	-.90	-.717	86.930	.475

Table 4.36 Planned comparison: Question 2.2

Dependent variable	Value of Contrast	t	df	Sig. (2-tailed)
Total depression	-2.50	-1.644	77.806	.104
Total anxiety	-1.70	-1.289	77.272	.201

Table 4.37 Planned comparison: Question 2.3

Dependent variable	Value of Contrast	t	df	Sig. (2-tailed)
Total depression	3.42	2.133	87.695	**.036**
Total anxiety	.80	.606	84.328	.546

Table 4.38 Planned comparison: Question 2.4

Dependent variable	Value of Contrast	t	df	Sig. (2-tailed)
Total depression	-3.90	-2.470	87.321	**.015**
Total anxiety	-2.84	-1.969	87.916	**.001**

The following group comparisons were analysed for each research question (as stated above on p. 166):

For question 2.1, the HIV+ group was compared with those newly on HAART (Table 4.35). They did not differ significantly with respect to either symptoms of depression or anxiety. For question 2.2, those mothers newly on HAART were compared with those who had been on HAART for 6 months (Table 4.36). Again, no significant differences were found on either measure of psychological adjustment. For question 2.3, those on HAART for 6 months were compared with HIV positive women not yet on treatment and found to differ significantly with regard to levels of depression, but not anxiety (Table 4.37). Finally, results for question 2.4 revealed significant differences in levels of depression and anxiety between mothers on HAART for 6 months and the control group of HIV negative women (Table 4.38).

These combined results indicated that levels of anxiety remained higher in HIV positive compared with HIV negative mothers, regardless of whether antiretroviral therapy had been commenced or for how long. At 6 months, mothers on antiretroviral therapy still exhibited levels of anxiety significantly higher than that of HIV negative mothers. In contrast, levels of depressive symptoms were significantly lower amongst mothers on antiretroviral therapy for 6 months than those who had just commenced treatment. However, 6-month levels of depressive symptoms, as with anxiety, remained higher than those of HIV negative mothers.

4.3.2 Multivariate analysis

Research question 2.5 considers whether the psychological adjustment of mothers on antiretroviral therapy can be predicted by changes in health, either perceived or actual. To address this question, Multiple Regression was used. Changes in CD4 count and ART side-effects (objective health measures) and change in perceptions of physical health (subjective health measure) were regressed onto the two dependent variables. While change in viral load was also assessed, the amount of missing data[45] for this variable meant that its inclusion would have rendered the sample size too small to conduct a regression analysis. Nonetheless the remaining variables are the key means of assessing and reporting on the health status of patients on HAART. While clinical stage is also a useful indicator of the health status of HIV-infected populations, since patients are not re-staged after commencing HAART, this cannot be used as a measure of change.

Table 4.39 Regression model summary and coefficients: Total depression (n=37)

Model	Unstandardized coefficients		Standardized coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	11.535	2.636		4.375	.000
Change # ART side-effects	.006	.663	.002	.009	.993
Change perception physical health	.705	.691	.178	1.020	.315
Change CD4 count	.013	.015	.163	.876	.388
Overall: adjusted R^2 = -.023					

Table 4.40 Regression model summary and coefficients: Total anxiety (n=37)

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	32.209	2.469		13.044	.000
Change # ART side-effects	-.491	.621	-.151	-.791	.435
Change perception physical health	.425	.648	.116	.656	.516
Change CD4 count	.004	.014	.048	.254	.801
Overall: adjusted R^2 =-.047					

[45] This is due to the fact that the clinic was behind in the collection of bloods to evaluate viral load, resulting in missing data from files that were consulted.

Both regression models indicated that changes in perceived and actual health were not significant predictors of the psychological adjustment of HIV positive mothers while on antiretroviral therapy (see Tables 4.39 and 4.40 above). In fact, changes in health as measured both by women's perceptions and objective health markers (CD4 count and number of medication side-effects) account for less than 5% of the variance in psychological outcomes (depression: adjusted R^2=-.023; anxiety: adjusted R^2=-.047). Further, bivariate analyses (reported later in Table 4.35) had also failed to reveal a significant association between each of the three variables and HIV positive mothers' depression and anxiety scores. At least in the present sample, there is therefore no demonstrable association between changes in health related to being on antiretroviral therapy and psychological wellbeing. In addition, exclusion of somatic items on the depression scores did not impact substantially on either the overall variance accounted for by the regression model or the predictors that emerged as significant (see Appendix M for further details).

Finally, diagnostics were run in order to assess the quality of the models and the violation of assumptions. (See Appendix K for the distribution of the standardised residuals for each model presented using a histogram, a normal P-P plot and a scatterplot.) Both sets of diagnostics revealed some departures from the ideal distribution: The histograms had a concentration of points in the centre and were positively skewed, while the scatterplots showed greater spread at higher levels of the dependent variable, most noticeably for symptoms of anxiety. For this reason, comparative models were produced after applying a log transformation to each of the dependent variables. However, transformation failed to impact on the model and consequently only the results of the untransformed data have been presented for interpretation (see Appendix M for a summary).

4.4 SOCIO-DEMOGRAPHIC, CARE, HEALTH AND MENTAL HEALTH-RELATED PREDICTORS OF PSYCHOLOGICAL ADJUSTMENT

The third part of the analysis addressed which socio-demographic, poverty, care, health and mental health-related factors predicted the psychological adjustment of HIV positive mothers (research question 3).

4.4.1 Data reduction and bivariate analysis

In order to further explore the finding that HIV-infected mothers exhibited poorer psychological adjustment than non-infected mothers, question 3 employed Multiple Regression to test the predictive effect of a range of potential independent variables that could have accounted for this difference.

To begin with, given the largest possible sample size for this analysis (n=130 HIV-infected mothers), it was necessary to reduce the substantial set of potential predictors. To this end, a two-stage approach was adopted. First, theory and prior research was used to reduce the predictors conceptually and, second, exploratory data analysis was employed to further identify those predictors significantly associated with one or both of the outcome measures. While it may have been of interest to explore this question separately for women with and without access to HAART as well, the sample size (and therefore power) would have been significantly reduced.

4.4.1.1 Conceptual reduction

Table 4.41 below presents the entire set of predictors based on the conceptual reduction, together with the results of statistical analyses of their association with depression and anxiety scores. For this first part of the discussion, only the domain and variable name in the table (4.41) are referred to.

Table 4.41 Reduced set of predictors for regression modelling

Domain	Variable	N	Outcome measure:			
			Depression		Anxiety	
			F/r	p-value	F/r	p-value
Socio-demographic factors:	Age	180	r=-.202	**p=.006**	r=-.173	**p=.006**
	Education deprivation	179	F=16.389	**p=.000**	F=7.932	**p=.000**
	Employment deprivation	180	F=2.077	p=.151	F=1.264	p=.262
	Partner status	180	F=1.436	p=.241	F=2.992	*p=.053*
	Other adult females	180	F=.199	p=.656	F=.250	p=.618
	Over 60s	180	F=.561	p=.455	F=.145	p=.704
Poverty/income-related factors:	Total individual income	180	r=-.025	p=.741	r=.026	p=.733
	Income & material deprivation	180	F=6.499	**p=.012**	F=.995	p=.320
	Living environment deprivation	180	F=1.857	p=.175	F=2.062	p=.153
	Cash or kind remittances	180	F=2.791	*p=.097*	F=.385	p=.536

	Regularity of HH income	180	F=5.728	**p=.018**	F=.106	p=.745
Care-related factors:	# HH children prim carer for	180	r=.097	p=.225	r=.034	p=.651
	HIV+ child	180	F=3.229	*p=.074*	F=2.163	p=.143
	Under 6s	180	F=1.324	p=.251	F=.017	p=.897
	Special care for adults	180	F=2.983	*p=.086*	F=.584	p=.446
	Childcare help	180	F=.663	p=.417	F=.320	p=.572
General health-related factors:	Hospitalisation	180	F=5.036	**p=.026**	F=2.804	*p=.096*
	History of TB	180	F=18.134	**p=.000**	F=5.561	**p=.019**
	Chronic health problems	180	F=1.177	p=.279	F=1.412	p=.236
	Perception physical health	180	r=-.360	**p=.000**	r=-.318	**p=.000**
HIV health-related factors:	HIV status	180	F=22.276	**p=.000**	F=11.682	**p=.001**
	Partner/HH member HIV+	180	F=3.051	*p=.082*	F=.111	p=.740
	CD4 count	124	r=.003	p=.970	r=-.079	p=.384
	ART status	130	F=2.628	*p=.107*	F=.002	p=.964
	Duration of ART	78	F=3.001	*p=.087*	F=1.725	p=.193
	# ART side-effects	80	r=.155	p=.169	r=.009	p=.935
HIV non-health related factors:	Time since diagnosis	125	r=.086	p=.340	r=.025	p=.781
	Attend HIV support group	130	F=9.915	**p=.002**	F=.029	p=.864
	Intentional disclosed	130	F=.547	p=.461	F=.010	p=.920
	# people disclosed to	130	r=-.036	p=.681	r=-.112	p=.205
	Disclosed to HH member	130	F=1.612	p=.206	F=.315	p=.576
	Disclosed to current partner	130	F=.000	p=.993	F=.016	p=.898
	Disclosed close female relative	130	F=1.331	p=.251	F=.016	p=.898
	Disclosed to friend	130	F=.017	p=.897	F=.153	p=.696
	Disclosed to child	130	F=.019	p=.890	F=.000	p=.991
	Disclosed to support network member	130	F=.361	p=.549	F=2.405	p=.123
Psychological factors:	Total support	180	r=-.001	p=.992	r=-.273	**p=.000**
	Total satisfaction	180	r=.311	**p=.000**	r=.303	**p=.000**
	Availability tangible support	180	r=-.004	p=.957	r=-.221	**p=.003**
	Availab. affectionate support	180	r=-.103	p=.168	r=-.245	**p=.001**
	Availability positive social interaction	180	r=-.137	*p=.067*	r=-.276	**p=.000**
	Availability emotional/ informational support	180	r=.145	*p=.052*	r=-.180	**p=.015**
	Satisfaction tangible support	180	r=-.208	**p=.005**	r=-.184	**p=.014**
	Satisfac. affectionate support	180	r=.288	**p=.000**	r=-.287	**p=.000**
	Satisfaction: positive social interaction	180	r=.282	**p=.000**	r=.270	**p=.000**
	Satisfaction emotional/ informational support	180	r=-.166	**p=.026**	r=-.179	**p=.016**
	# support network members	180	r=.091	p=.227	r=.064	p=.395
	Support from HH member	180	F=.149	p=.700	F=1.672	p=.198
	Support from current partner	180	F=1.048	p=.307	F=4.415	**p=.037**
	Support close female relative	180	F=5.166	**p=.024**	F=.040	p=.841
	Support from friend	180	F=5.166	**p=.014**	F=.264	p=.608
	Active coping	180	r=-.107	p=.153	r=-.265	**p=.000**
	Avoidant coping	180	r=.542	**p=.000**	r=.392	**p=.000**
	Religion & self distraction	180	r=.133	*p=.075*	r=-.141	*p=.059*
	Substance use	180	r=.177	**p=.017**	r=.244	**p=.001**
	Humour	180	r=.179	**p=.016**	r=-.113	p=.130

Bold: p<0.05, 2-tailed
Italics: 0.05<p<0.10, 2-tailed

The important conceptual reductions were made in the socio-demographic and poverty/income-related domain. Noble et al.'s (2006a) Index of Multiple Deprivation, although developed for a different purpose, was considered an appropriate approach on which to model some of the attempts at data reduction in the present sample. The indices combined indicators into different domains and used this information to compare areas ranging from small-area level to provinces (in South Africa) in terms of their levels of domain-specific and overall deprivation. For this study, four of Noble et al.'s five domains were relevant: Income and Material Deprivation, Employment Deprivation, Education Deprivation and Living Environment Deprivation.

For the first three domains, Noble et al.'s (2006a) exact approach was applied[46]. Income and Material Deprivation meant that the individual participant met at least one of the following criteria: lived in a household with a household income below 40% of the mean equivalent household income; lived in a household without a fridge; or lived in a household with neither a television nor a radio. Employment Deprivation meant that the participant, if aged 15 to 65 years, was unemployed according to the official definition[47] or, if over 65 years, was not working due to illness or disability. Education Deprivation was defined as having no schooling at secondary level or above (i.e. beyond grade 7). For Living Environment Deprivation, only four of Noble et al.'s six indicators could be derived based on the data collected and the domain was therefore defined in the following way: the participant lived in a household without piped water in their dwelling or yard or within 200 metres; lived in a household without a pit latrine with ventilation or flush toilet; lived in a household without access to a telephone; or lived in a household with two or more people per room. It was decided to apply this deprivation domain despite the absence of data for two indicators because the four indicators alone classified 93% (168 out of 180) of the sample as experiencing living environment deprivation. It was therefore unlikely that the addition of two more indicators would substantially affect either the classification of individual participants or the results of subsequent analyses.

[46] See Noble et al.'s main (2006a) and technical reports (2006b) for further details.

[47] The official definition of employment defines the unemployed as people within the economically active population who (a) did not work in the seven days prior to Census night, (b) wanted to work and were available to start work within a week of Census night, and (c) had taken active steps to look for work or start some form of self-employment in the four weeks prior to Census night (Noble et al., 2006b). This is in contrast with the expanded definition that also includes individuals who fulfil the above criteria, but did not take active steps to seek work.

The table below (4.42) summarises the sample statistics when applying the above deprivation approach:

Table 4.42 Summary statistics for types of deprivation

Domain	Frequency	Percent
Income and material deprivation	159	88.3
Employment deprivation	123	68.3
Education deprivation	40	22.3
Living environment deprivation	168	93.3

With respect to Income and Material Deprivation, sensitivity testing was also conducted in order to evaluate the impact of amending the household income on which the indicator was based for certain cases in the sample. In 18 cases the participant was unable to report the income of one of the household members, resulting in the total for household income (based on known income only) significantly misrepresenting total income. Concerns regarding misrepresentation were based on the fact that available information suggested that the individuals with unknown income were usually breadwinners whose income constituted a significant contribution to the household. However, sensitivity testing showed that the net effect of amending household income by estimating the income of these household members (based on the approximate income of other persons in the sample in the same employment) was that one less case would be classified as deprived (see Appendix M for details). Consequently the data was not altered.

Apart from the application of Noble et al's (2006a) deprivation approach, several other decisions were taken. With respect to the socio-demographic factors reported in Table 4.48 above, age and education (deprivation) were retained in order to be used as control variables in regression analyses. The study took the approach of sampling from an area that is relatively homogenous socio-economically; however, the groups were not matched on specific criteria (further details were discussed in Chapter 3). Age and level of education were nonetheless considered two important variables, the impact of which could be controlled for statistically.

Of the potential variables derived from data on household composition, only two were retained: presence of household members over 60, and other adult females. Pilot work, supported by other research in low-income communities, indicated that adult females, particularly sisters and mothers, often play very important supportive roles (Brandt, 2005a; Winstead et al., 2002). Further, the Old-Age Pension earned by over 60s in South Africa is oftentimes a source of financial support for entire households, particularly in the poorest areas where HIV prevalence is also high (Lund, 1999). Consequently, both these factors could be indicative of the availability of various sources of support, both emotional and instrumental, and were therefore considered relevant to the question of psychological adjustment explored in the regression analyses.

4.4.1.2 Technical and statistical reduction

As noted, technical considerations and statistical analyses were subsequently applied with a view to data reduction. To evaluate the association with depression and anxiety scores, categorical variables, all of which were dichotomous except for partner status, were tested using one-way ANOVAs and continuous variables using correlational analyses. The relevant F-statistic or Pearson's r is reported together with the p-value (see Table 4.41 above).

With regard to technical considerations, several dichotomous variables were omitted from analyses due to small cell sizes. For example, only four participants reported providing childcare outside of the household ("Care for non-HH children"), only eight participants had a partner on antiretroviral therapy ("Partner on ARVs"), and no household members attended an HIV-related support group ("HH member in support grp"). Variables with small cell sizes were only retained where they were considered particularly theoretically interesting in terms of their impact on psychological adjustment (for example, having an HIV-infected child). In the case of mental health history, which comprised five potential predictors, the limited number of responses meant that none of these predictors could be retained. They have, however, been presented as part of the descriptive data already discussed (see section 4.3.2). For non-dichotomous nominal variables with small cell sizes, levels were collapsed in order for the variable to be retained. For example, the variable assessing the period of time participants had been hospitalised in the six months prior to

interview had to be changed from an ordinal variable with five levels (None, Less than a week, Less than a month, One to three months, More than 3 months) to a dichotomous one (Recently hospitalised, Not recently hospitalised). Finally, two variables with several missing data values ("Time until 1st disclosure" and "Time since 1st disclosure") were omitted in order to preserve sample size for regression analyses.

The results of statistical analyses produced a further reduced set of potential predictors significantly associated with the dependent variables (see Table 4.41 for details). In the present sample, higher levels of depression were associated with being older; having less education; living in a household with irregular income, and more income and material deprivation in general; being HIV-infected; being hospitalised, having tuberculosis in the previous year; having a poorer perception of one's physical health; and attending an HIV-related support group. In addition, being less satisfied with one's social support, both overall support and different types of support (tangible, affectionate, positive social interaction and emotional/informational support); not receiving support from a close female relative, and a friend; using generally avoidant coping strategies, and using substances and humour as a form of coping were associated with experiencing more depressive symptoms. Other results that approached significance (i.e. p-value between .05 and .10) were not receiving cash or kind remittances; having an HIV-infected child or partner or household member; providing special care for adults; not being on antiretroviral therapy (ART) or being on ART for a shorter period of time; the lack of availability of positive social interaction and emotional/informational support; and using religion and self-distraction as a coping strategy.

With respect to anxiety, numerous variables were also found to be associated with levels of anxiety symptoms. Greater anxiety (at the 5% level) was predicted by: higher age; less education; being HIV-infected; having a history of tuberculosis in the previous year; poorer perception of one's physical health; less available social support, both overall support and different types of support (tangible, affectionate, positive social interaction and emotional/ informational support); being less satisfied with one's social support, both overall support and different types of support; not receiving support from a partner; using less active coping and more avoidant coping, and using substances as a coping strategy. As with depression, some further results approached significance, but did not meet the 5%

strategy facilitated the investigation of the impact of HAART access, a question of interest to academics and policymakers alike (see discussion in Chapter 1).

Finally, due to the large number of positive findings for both outcome variables, in the main, only those significant at the 5% level were retained for use in regression analyses. Some exceptions were made for specific models because other potential predictors were of theoretical interest. These will be discussed later where relevant.

4.4.2 Multivariate analysis

To address research questions 3.1 and 3.2, two regression models (one for each outcome measure) were developed for HIV positive women using the reduced set of predictors.

4.4.2.1 Depression model

For the first model (n=123), the following 11 independent variables were regressed on depression scores: Income and material deprivation and Regularity of household income (poverty-related factors); CD4 count, ART status, Recent hospitalisation and Perception of physical health (health-related factors); and Attending HIV support group, Total satisfaction, Avoidant coping, Substance use and Humour (mental health factors) (see Table 4.43 below). In addition, Age and Education deprivation were included as control variables (since groups had not been explicitly matched on these criteria). Diagnostics were also run in order to assess the quality of the models and the violation of assumptions.

Table 4.43 Regression model summary and coefficients: Total depression (n=123)

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	24.755	7.123		3.476	.001
Age	.063	.069	.069	.915	.362
Education deprivation	-1.316	1.229	-.081	-1.070	.287
Income and material deprivation	-1.007	2.117	-.033	-.476	.635
Regularity of HH income	**3.050**	**1.559**	**.163**	**1.957**	**.053**
CD4 count	.004	.003	.093	1.020	.310
ART status	.710	1.518	.046	.468	.641
Recent hospitalisation	-1.575	1.480	-.081	-1.065	.289
Perception of physical health	**-1.037**	**.487**	**-.174**	**-2.128**	**.036**
Attending HIV support group	*-2.182*	*1.244*	*-.145*	*-1.753*	*.082*
Total satisfaction	-.130	.223	-.047	-.586	.559
Avoidant coping	**3.628**	**.747**	**.436**	**4.857**	**.000**
Substance use	-.564	.572	-.071	-.986	.326
Humour	-.057	.676	-.007	-.085	.932
Overall: adjusted R^2= .436					

Bold: p<0.05
Italics: 0.05<p<0.10

Results showed that the model accounted for 43.6% (adjusted R^2=.436) of the variance in depression scores, with three predictors emerging as significant at the 5% level (see Table 4.43 above). Irregular household income, poorer perceived physical health and the use of avoidant coping were independently significant predictors of adjustment, predicting higher levels of depressive symptoms amongst HIV positive mothers. In addition, comparison of standardised beta coefficients indicated that avoidant coping was the best predictor of depression (std β=.436), with perceived health and regularity of household income both making smaller and approximately equal contributions (std β=-.174 and .163 respectively). While attending an HIV related support group approached significance as a predictor of lower levels of depressive symptoms, it did not meet the required level of significance (std β=-.145, p=.082).

Both sets of diagnostics revealed some departures from the ideal distribution (see Appendix K). The histogram was slightly positively skewed, while the scatterplot showed greater spread for middle of the range scores. However, the P-P plot showed a good fit for

the regression line. Although not strictly indicated by the diagnostics, as for the previous regression model, the impact of log transformation of the dependent variable was tested and found to be negligible (see Appendix M). Further, the exclusion of somatic items from depression scores was evaluated and found not to impact significantly on the model's explanatory power, reducing it by only 5% to 38% (see Appendix M).

Finally, two additional independent variables of theoretical interest were included in the model (despite not being associated with depression at the 5% significance level) in order to test their impact on the total variance (see Model 2 in Appendix M). However, neither having an HIV-infected child nor time since HIV diagnosis was a significant predictor of depression. Consequently, model 1 as reported above was retained.

Across the two models tested, only poverty-related (regularity of household income), health (perception of physical health) and mental health (avoidant coping) factors emerged as significant predictors of levels of depression. Socio-demographic factors were only included as control variables (age and education) and no care-related factors met the threshold for inclusion in the regression model (i.e. significantly associated with depression at the 5% level). The impact of having an HIV-infected child was nonetheless tested and found not to be significant. Other care-related factors included in the conceptual model, namely, the number of household children for whom the participant is the primary carer, whether or not the participant has assistance in her childcare role, whether or not she cares for a child or children under the age of six years, and whether or not she has additional non-childcare related care roles providing special care to adults, were also not significantly associated with depression scores. However, providing special care to adults approached significance as a factor associated with higher levels of depression (p=.086) despite not meeting the required level for testing.

4.4.2.2 Anxiety model

For the second model (n=123), Age and Education deprivation were included as control variables and a further ten independent variables regressed on anxiety scores: Partner status (comprising two dummies: Non-HH partner and HH partner), CD4 count, ART status, Perception of physical health, Total support, Total satisfaction, Active coping, Avoidant

coping, and Substance use (see Table 4.44 below). Further, appropriate diagnostics were run.

Table 4.44 Regression model summary and coefficients: Total anxiety (n=123)

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	38.119	6.493		5.871	.000
Age	.028	.071	.037	.395	.693
Education deprivation	-.431	1.173	-.032	-.368	.714
Non-HH partner	-1.733	1.268	-.141	-1.366	.175
HH partner	.431	1.492	.029	.289	.773
CD4 count	.000	.003	.014	.136	.892
ART status	-.211	1.409	-.017	-.150	.881
Perception of physical health	-.599	.457	-.121	-1.311	.193
Total support	.018	.066	.035	.277	.782
Total satisfaction	-.166	.244	-.073	-.681	.497
Active coping	**-2.484**	**.785**	**-.335**	**-3.164**	**.002**
Avoidant coping	**2.512**	**.633**	**.365**	**3.967**	**.000**
Substance use	*.911*	*.543*	*.138*	*1.677*	*.096*
Overall: adjusted R^2=.263					

Bold: p<0.05
Italics: 0.05<p<0.10

In contrast with the depression model, the regression model tested for anxiety accounted for only 26.3% of the variance in scores (see Table 4.44 above). Higher levels of anxiety scores were significantly predicted by the coping strategies of HIV positive women, both less use of active coping and greater use of avoidant coping. As with depression, avoidant coping emerged as the best predictor (std β=.365), although followed closely by active coping (std β=-.335) (see Table 4.44 above). While the results suggested a trend toward an association between higher levels of anxiety and the use of drugs or alcohol, this finding did not meet the 5% significance level set for testing (std β=.138, p=.082).

Diagnostics revealed a picture highly similar to the model tested for depression, although with a slightly poorer fit (as shown in the P-P plot – see Appendix K). Once again, a log transformation was conducted for comparative purposes only, with a less than one percent reduction in explained variance (adjusted R^2=.260 versus .263; see Appendix M).

Finally, the addition of two more independent variables of theoretical interest to the model (despite not meeting the 5% significance level for association with anxiety) was tested (see Model 2 in Appendix M). Neither experiencing income and material deprivation nor having an HIV-infected child was shown to be a significant predictor of anxiety in HIV positive mothers. Consequently, model 1 already reported above was retained.

Of the conceptual domains tested across the two models, only mental health factors (active coping and avoidant coping) significantly predicted levels of anxiety. Further, while poverty-related (Income and material deprivation) and care-related (having an HIV-infected child) factors were included in the second model for theoretical reasons, they were neither significantly correlated with, nor significant predictors of, anxiety scores. The model therefore provided no evidence that socio-demographic, poverty, care or health-related factors contributed significantly to the prediction of levels of anxiety symptoms in HIV-infected mothers.

With respect to the impact of factors beyond the individual, only one independent variable that met the threshold for inclusion in the regression models emerged as significant and only for one of the outcome measures. Results showed that in addition to factors specific to the individual (for example, coping strategies used and personal perceptions of health), the regularity of income to the household in which the HIV positive mother lived significantly predicted her levels of depression, but not anxiety. More regular household income therefore independently predicted lower levels of depressive symptoms (std β=.163, p=.053). However, this finding did not hold when somatic items were excluded from the depression score.

4.5 THE RELATIVE IMPACT OF HIV STATUS ON PSYCHOLOGICAL ADJUSTMENT

The final section of the statistical analysis addressed the relative impact of HIV status on the psychological adjustment of mothers living in a poor community (research questions 4.1 and 4.2). This comprised two components: first, whether or not HIV status predicted psychological adjustment after controlling for other relevant socio-demographic, poverty,

care, health and mental health-related factors (4.1); and second, whether HIV status was a better or worse predictor of psychological adjustment in mothers than these other factors (4.2).

4.5.1 Multivariate analysis

To address research questions 4.1 and 4.2, two regression models were developed incorporating all participants in the study (i.e. both the infected women included in the previous regression and the control group). HIV status was included as an independent variable in order to test the presence of a primary effect on psychological adjustment (question 4.1). In addition, other conceptually-relevant independent variables were tested alongside HIV status in order to evaluate their relative impact on psychological outcomes (question 4.2). Since the control group was included in these regression models, all HIV-specific variables not relevant to women in the control group had to be omitted (e.g. ART status, attending HIV related support group). In all other respects, the previous discussion on data reduction applies in the selection of predictors.

4.5.1.1 Depression model

In order to model predictors of depression (n=179), two control variables (Age, Education deprivation) were regressed onto depression scores together with the following nine independent variables: Income and material deprivation, Regularity of household income, HIV status, Recent hospitalisation, Perception of physical health, Total satisfaction, Avoidant coping, Substance use and Humour (see Table 4.45 below). Further, as with research question 3, appropriate diagnostics were run, and the impact of log transformation on the dependent variable and the exclusion of somatic items from depression scores tested.

Table 4.45 Regression model summary and coefficients: Total depression (n=179)

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	21.875	7.086		3.087	.002
Age	.052	.055	.055	.929	.354
Education deprivation	**-2.759**	**1.167**	**-.143**	**-2.365**	**.019**
Income and material deprivation	-.100	1.425	-.004	-.070	.944
Regularity of HH income	**3.091**	**1.177**	**.179**	**2.626**	**.009**
HIV status	**3.118**	**1.582**	**.174**	**1.971**	**.050**
Recent hospitalisation	-.713	1.246	-.033	-.572	.568
Perception of physical health	**-.909**	**.410**	**-.192**	**-2.218**	**.028**
Total satisfaction	**-.444**	**.200**	**-.133**	**-2.216**	**.028**
Avoidant coping	**3.635**	**.593**	**.399**	**6.129**	**.000**
Substance use	**1.050**	**.451**	**.126**	**2.329**	**.021**
Humour	*.938*	*.514*	*.105*	*1.825*	*.070*
Overall: adjusted R^2=.490					

Bold: p<0.05
Italics: 0.05<p<0.10

Overall, the regression model accounted for a substantial 49% of variance in depression scores (adjusted R^2=.490) (see Table 4.45 above). As with the regression model for HIV positive mothers, the diagnostics suggest that the model was relatively sound with respect to violation of assumptions (see Appendix K). The residuals were approximately normally distributed, except for a small tail to the right (i.e. positively skewed), there was only a slight pattern in the scatterplot, and the P-P plot revealed a relatively good fit for the predictor line. Thus the impact of log transformation on the dependent variable was tested only for comparative purposes and in the absence of a clear indication that these results should be substituted for the untransformed ones reported above (see Appendix M for detailed results). The transformed model explained 6% less of the variance (adjusted R^2=.432 versus .496) and retained most of the predictor variables, including those most relevant to addressing the present research questions (4.1 and 4.2). As with the previous research question, the presence or absence of somatic items only minimally affected the explanatory power of the model as well as the predictors that emerged as significant (see Appendix M).

With reference to question 4.1, the results showed that HIV status had a significant, independent impact on levels of depressive symptoms in mothers (living in a low-income

community), even after controlling for a range of other variables (see Table 4.45 above). However, with reference to question 4.2, there were other psychological, health-related and demographic factors that also significantly predicted depression and even had a greater predictive effect. As with HIV-infected women, the use of avoidant coping was the best predictor of depression, predicting higher levels of depressive symptoms (std β=.399, $p<.05$). This was followed by poorer perceptions of physical health, with a substantially lower standardised beta coefficient (std β=.192, $p<.05$) and regularity of household income (std β=.179, $p<.05$). Lower levels of education (std β=.-.143, $p<.05$), followed by lower levels of satisfaction with social support (std β=-.133, $p<.05$) and the use of substances (std β=.126, $p<.05$) were also associated with higher levels of depressive symptoms, but with less predictive effect than HIV status. Significant factors more predictive of depression than HIV status therefore fall within the domains psychological (coping) and general health (perceived wellbeing), and those less predictive within psychological health (coping, social support) and socio-demographic factors (education). The income/poverty-related domain (regularity of household income) had an almost equal predictive effect when compared with HIV status in the present model (std β=.179 versus .174).

Finally, one more independent variable of theoretical interest was added to the model, namely, having an HIV-infected child (its correlation with depression had approached, but not reached significance; p=.074) (see Model 2 in Appendix M). However, since results revealed minimal impact on both the significant predictors and the overall variance explained by the model, the model reported above was retained.

4.5.1.2 Anxiety model

To evaluate the impact on anxiety (n=179), two control variables (Age, Education deprivation) were regressed onto anxiety scores together with the following nine independent variables, two of which were dummies: Non-household partner and Household partner (dummy variables for partner status), HIV status, Perception of physical health, Total support, Total satisfaction, Active coping, Avoidant coping, and Substance use. Diagnostics were also run and the results of a log transformation of the dependent variable presented for comparative purposes (see Appendices K and M respectively).

Table 4.46 Regression model summary and coefficients: Total anxiety (n=179)

Model	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	41.731	6.787		6.149	.000
Age	.056	.055	.072	1.018	.310
Education deprivation	-.917	1.124	-.057	-.816	.416
Non-HH partner	-1.086	1.096	-.081	-.990	.324
HH partner	.691	1.273	.044	.542	.588
HIV status	.726	1.414	.049	.513	.608
Perception of physical health	-.427	.382	-.109	-1.116	.266
Total support	-.069	.059	-.117	-1.166	.245
Total satisfaction	-.145	.234	-.052	-.620	.536
Active/adaptive coping	-.856	.644	-.120	-1.329	.186
Avoidant coping	**2.753**	**.512**	**.365**	**5.372**	**.000**
Substance use	**1.587**	**.436**	**.231**	**3.637**	**.000**
Overall: adjusted R^2=.320					

Bold: p<0.05
Italics: 0.05<p<0.10

The overall model accounted for 32% of the variance in anxiety scores (adjusted R^2=.320) and was generally sound, although with a poorer fit than the depression model (see Table 4.46 above). Nonetheless, there were not substantial violations of assumptions, as demonstrated both by the scatter of residuals on the scatterplot and the relatively normal distribution of residuals. The distributions were positively skewed. Comparative results based on the log transformation of anxiety scores did not affect either the predictors that emerged as significant or the amount of variance explained by the model (adjusted R^2=.329 versus .320; results are presented in Appendix M).

In addressing the relevant research questions (4.1 and 4.2), the analysis revealed quite different results to those presented for the model of depression. In contrast with depression, HIV status did not have a significant, primary effect on anxiety scores (std β=.049, p>.05) (see Table 4.57 above). However, as with the model for HIV positive mothers, coping strategies were the best (and only significant) predictor of levels of anxiety symptoms in mothers living in low-income communities. Avoidant coping had the largest predictive effect (std β=.365, p<.05) followed by substance use (std β=.231, p>.05), both of which predicted higher levels of anxiety.

Finally, the impact of two additional variables of interest (having an HIV-infected child and experiencing income and material deprivation) were tested and found to have no impact at all (see Model 2 in Appendix M). Both the explained variance and the significant predictors remained unchanged. The original model was therefore retained and only its results reported in full.

CHAPTER 5. RESULTS II: LONGITUDINAL CASE STUDIES

This chapter focuses on the longitudinal, qualitative study outlined in Chapter 3. To begin with, the approach taken to the analysis of data will be outlined, including its theoretical underpinnings. Second, a brief sketch of each of the five case studies on which the analysis draws will be provided. Third, the analysis itself will be presented, drawing on the concepts of disruption, chaos/loss, restitution/normalising and quest/growth. Finally, reference will be made to the quantitative study where relevant, and in anticipation of a more formal attempt to integrate the study's findings in Chapter 6.

5.1 THE APPROACH TO QUALITATIVE ANALYSIS

5.1.1 A narrative approach

Narrative analysis was chosen as an appropriate approach to analyse the transcripts of multiple interviews conducted with each of the five women and thereby articulate their individual perspectives (further details were provided in Chapter 3, section 3.4.2). Narratives are an account of events that happen over time (temporality; Bruner, 1991; Riessman, 1993) and take particular events, episodes or experiences as their reference point (emplotment and particularity; Bruner, 1991). Narratives are therefore concerned with representing specifics rather than generalities, rendering them deeply situated and contextual, a contribution of importance to the present study (Squire, 2005). Further, the particularity of narrative renders narrative analysis well suited to case studies that aim to contribute depth and breadth to the understanding of a subject.

A narrative approach draws on the principle that telling stories[48] is a defining aspect of human experience since it is through this process that individuals construct, interpret and

[48] The debate regarding the differentiation of the terms 'narrative' and 'story' is not important for the present analysis, thus the terms will be used interchangeably.

make meaning of experience (Bruner, 1991; Sarbin, 1986; Widdershoven, 1993). Expressed differently, Bruner (1991, p. 4) argues that "we organize our experience and our memory of human happenings mainly in the form of narrative – stories, excuses, myths, reasons for doing and not doing, and so on." The narrator is removed from the experience, for stories interpret rather than reflect experience, and thus the self that is remembered and storied in narrative is always different from the 'historical self' (Bruner, 1994; Widdershoven, 1993). As Frank (1995, p. 22) argues, "The stories we tell about our lives are not necessarily those lives as they were lived, but these stories become our experience of those lives." While this means that narratives cannot be assumed simplistically to have correspondence with their narrators' emotional wellbeing, they have the advantage of reflecting psychological perceptions and interpretations of 'objective' events (Parker, 2005; Squire, 2005). This is important for the present study given the aim to employ the case studies to contribute to, and complement, the population-based approach of the cross-sectional study.

Finally, the analysis will also not assume that emotion only exists in narrative where it is expressed and articulated with words. Later analysis will draw on the work of Craib (2000) and Hollway and Jefferson (2000) in particular to incorporate two insights into the analysis: that a focus on the unconscious can be useful, and that people sometimes express emotions in ways in which they cannot recognise them as emotions. In order to achieve this objective, the analysis will also adopt Craib's position that it is necessary to look at both the creativity of people's narratives and the reality of their lives (as well as the meaning of the difference). This will mean thinking about how women present themselves in the narratives (the performance) and the contextual realities of their lives as necessary parts in developing a thorough understanding of their experience.

5.1.2 A theoretical framework: illness narratives and biographical disruption

5.1.2.1 Introduction

The work of Michele Crossley (2000) on HIV narratives, Arthur Frank (1995) on chronic illness narratives, and Michael Bury (1982) on biographical disruption in the context of chronic illness provided a useful collective point of departure for the analysis. Crossley's

empirical work was conducted with a group of long-term survivours of HIV in the UK, most of whom were educated, asymptomatic gay men (see Crossley, 1997 for more details). The research was conducted in the early 1990s, a time when long-term survivors of HIV were few, and even fewer were women (thus the small proportion of women in Crossley's sample). In contrast, Frank's work, published in the mid-1990s, was based on years of formal research and informal contact with people living with a range of chronic illnesses in the US. Also addressing chronic illness, Bury's work was conducted with rheumatoid arthritis patients in the late 1970s in North-West England and consisted mostly of women (given the four times higher prevalence of the disease among women than men). Both the latter samples comprised mainly people with working class backgrounds and therefore unlike Crossley's educated, relatively middle-class men and women.

The differences between these three bodies of work, and between their contexts and those of the present study, will become the subject of further discussion at a later point. As noted in Chapter 2, HIV differs in some respects from other chronic illnesses. Thus the experiences of gay HIV-infected men in the UK (Crossley, 2000), heterosexual HIV-infected women in South Africa, and those with non-HIV related chronic illnesses in the UK and US (Bury, 1982; Frank, 1995) are likely to be different in at least some respects. Socio-economic status and access to resources (including medical treatment, such as HAART) are just two of the important characteristics that differentiate these groups and inform a thread that emerges in the analysis concerning the situatedness of narrative. However, despite the fact that the stories told by Frank, Crossley and Bury's narrators may not necessarily be reflected in those of low socio-economic status South African women, their work represents three useful contributions to the application of narrative theory to the study of the subjective experience of illness (see Kleinman, 1998 for another important contribution). While Bury's and Frank's work was not developed with PLWHA, Bury's framework has been employed more recently with HIV-infected women of diverse socio-economic backgrounds in the US (Ciambrone, 2003). Further, Crossley (2000) herself has drawn attention to the analogies between her work and that of Frank's. This analysis will also demonstrate how Bury's theoretical contribution can be located within the narratives outlined by Frank and Crossley.

5.1.2.2 The Theory

For Frank, three underlying illness narratives - restitution, chaos and the quest narrative - are told "alternatively and repeatedly" in any illness (1995, p. 76). While narratives are always individualistic and personal, Frank argues that the "particularity of any experiential moment can ... be described by the narrative type that predominates at that moment" (ibid).

In contrast with Frank, Crossley is a psychologist concerned with trauma, and HIV as a potential trauma and source of disturbance and disruption. However, she similarly outlines three core HIV/illness narratives, each with a corresponding temporal orientation: the conversion or growth story, the normalising or external story, and the story of loss. A key element of Crossley's (2000, p. 137) theory is that HIV results in "the disturbance and disruption of [one's] fundamentally experienced sense of 'lived time'". Individuals can no longer be complacent in their assumptions about a future, causing their security in the world as well as their sense of identity, self-concept and moral responsibility to be challenged.

The strongest parallel between Frank's and Crossley's contributions is between the former's quest narrative and Crossley's growth story[49]. The quest narrative centres on the individual who "meets suffering head on; ... accept[s] illness and seek[s] to use it" in a purposeful way (Frank, 1995, p. 115), while the conversion or growth story similarly represents an individual who has achieved spiritual growth and renewed meaning in life as a result of HIV (Crossley, 2000). This growth allows the individual to engage more fully in the present (ibid). While Frank is less explicit about outcome and consequence than Crossley, focusing instead on the journey, both narratives refer to illness as a positive, learning experience for the individual.

The restitution narrative is concerned with returning the sick person to prior health and thereby gaining restitution (Frank, 1995). It perpetually reminds one that it is a narrative about health, and that illness is an aberration in an otherwise normal passage of time; time

[49] Another related concept that has emerged in the HIV/AIDS literature is posttraumatic growth. For more, see the tool box in Mental Health AIDS, "From surviving to thriving: HIV-associated posttraumatic growth" (Center for Mental Health Services (CMHS), 2007).

and life must be returned to its trajectory into a future undisrupted by illness. The restitution narrative therefore promises the possibility of outwitting suffering since a solution will emerge if the ill person acts in some way (Crossley, 2000). Therein is the parallel with Crossley's normalising narrative in which the narrator is leaning toward a future s/he is unable to relinquish in order to face the possibility of death. Consequently, s/he must minimise the impact of a positive diagnosis on future plans. The narrative is therefore an external story or one that minimises the impact of diagnosis and living with HIV.

Finally, Frank's (1995, p. 101) chaos narrative is characterised by the absence of order and purpose. The narrator cannot imagine life getting better, and feels out of control and subjected to "emotional battering". The ill person thus experiences "vulnerability, futility and impotence" (Frank, 1995, p. 97). This is closest to Crossley's remaining HIV narrative, the story of loss, in which the person with HIV lives in an empty present, unable to project into the future or to live with hopes and aspirations. The individual is therefore stuck in a present that is lived out of fear of the future and (sometimes) with nostalgia regarding the past. While the term "chaos" (Frank) has quite different connotations to "loss" (Crossley), there is a sense of stuckness consequent on illness in both the chaos narrative and the story of loss. In addition, there is a notion of disruption in these narratives that is explicitly part of Crossley's discourse but not Frank's, and that suggests a potential correspondence with Bury's (1982) theory of biographical disruption.

Biographical disruption occurs as a result of the challenge posed by chronic illness to the individual's everyday life and fundamental belief systems (Bury, 1982). For Bury, disruption manifests in relation to taken-for-granted assumptions and behaviours, self-concept, and the mobilisation of resources. Further, like chaos and loss, disruption is about disturbance - either psychically, philosophically or behaviourally. The concept of disruption therefore has a useful overlap with Crossley's and Frank's narratives. In all three, the ill person succumbs in some way to the disease, which is different from a narrative that reveals growth or one that embodies the promise of things becoming 'normal' again.

5.1.3 The form of the analysis

Some final summary comments regarding the form of the analysis undertaken in this study are also in order. As already indicated, the analysis drew on a narrative approach while also considering the relevance of Crossley's, Frank's and Bury's work for the present study. This means that not all nuances and sub-narratives in the interview transcripts were pursued. However, those that had implications for the analysis, either because they supported, challenged or contributed to the three core illness narratives that were considered, will be discussed. As noted earlier in this section (5.1), such decisions were also driven by an awareness of the study's triangulated design and its policy orientation. This rendered it particularly important to conduct a clear and focused analysis, while still remaining rigorous and theoretically sound within the demands of the paradigm and chosen analytic approach (Morse, 1991). Such demands include shedding light on contradiction, shifts and confusion where they emerge in participants' talk as well as the sometimes in-process, unfinished nature of stories that describe lived time (Ezzy, 2000). These elements will also form part of the analysis presented.

Finally, at different points in the analysis, brief reference will be made to several different cases, while a more detailed consideration of an individual case will be used to develop and illustrate an argument at other points.

5.2 THE CASE STUDIES

Before presenting the formal analysis, the five women who were selected as case studies will be introduced. Each brief outline provides background information regarding the women as individuals and members of a household, as a context for reading the specifics that will be drawn on in the analysis. In addition, an overview of their physical health and HIV-related experience is provided. Further details will be presented where relevant during the course of the analysis.

These case studies reflect the situation at the time that the women first began participating in the study (time 1). However, as the subsequent analysis will suggest, aspects of their

situation changed over the six-month period that the case studies were developed. This presentation is intended both as an introduction to the women, and as the basis for later commentary on the contribution of the case study approach to understanding women's experiences of living with HIV.

Case 1: Lindiwe[50]

Lindiwe is 31 years old, unemployed and receives a disability grant. She has a grade 8 education. She lives with her mother, two brothers, an adult niece, and an eight-year-old nephew and ten-year-old niece for whom she helps provide care. She has no children of her own and is not in a relationship. The household has access to a tap in the yard and a toilet outside of the yard. Lindiwe's mother receives a pension, her brother has a part-time job, and one of the children receives a child support grant. There is no other source of material support to the household and she reported that they often go without food.

Lindiwe tested HIV positive six years previously and had a CD4 count of 263. She rated her physical wellbeing as very poor (2/10), and had been sickly with TB for a long time as well as being hospitalised for nearly two of the previous six months. She also had a history of asthma. Lindiwe disclosed her HIV status to her mother one year after diagnosis and to her cousin who lives in the same neighbourhood four years after that. Her mother, two brothers and an aunt are her sources of support, and she does not attend an HIV-related support group. Lindiwe attends church on a daily basis.

Case 2: Pumza

Pumza is 40 years old and lives in a one-room shack with her nine-year-old daughter, her thirteen-year-old nephew, and her eleven- and twenty-two-year-old nieces. The shack has an outside tap and there is a toilet outside of the yard. Pumza has a grade 8 education and receives a disability grant. Neither she nor her adult niece is employed, and the household does not receive either formal or informal support in the form of food or other goods on a regular basis. However, the household is rarely without food. The eleven- and thirteen-year-olds are partly sustained through child support grants that their mother, Pumza's sister, receives for each of them.

Pumza rated her physical wellbeing as fairly good (7/10) and had not been hospitalised recently although she had been ill with TB in the previous year. She tested HIV positive five years previously and had a CD4 count of 206. Pumza had been receiving ARVs for six months and after numerous initial side-effects, reported an improvement in her physical wellbeing. She was not attending a formal HIV-related support group, and considered a friend to whom she had disclosed her HIV status one year after diagnosis and who was also on ARVs as her main source of support. Three years later, Pumza also disclosed her HIV status to her mother, sister, brother and niece (who lived with her). She disclosed to her ex-partner two months later when commencing antiretroviral treatment.

[50] In order to protect the anonymity of the women interviewed, pseudonyms have been used.

Case 3: Zoleka

Zoleka is 47 years old, has no formal education and lives with her two adolescent daughters (14 and 17 years), their infant children (3 and 12 months respectively), and a clan cousin and his girlfriend. While her cousin is employed, neither Zoleka nor the children receive a regular source of income, and they are not supported in any way through the cousin's income. The house has both a tap and a toilet in the yard. The family receives food parcels from friends or neighbours at times, but mainly relies on waiting for food distributed at the clinics or occasionally begging in nearby, wealthier townships. They often go hungry.

Zoleka rated her physical wellbeing as below average (4/10), and had recently been treated for TB as well as spending time in hospital. She was diagnosed HIV positive one year previously after her boyfriend died of AIDS, and had just commenced antiretroviral treatment. She was not attending an HIV-related support group and had only disclosed her HIV status to her fourteen-year-old daughter who she also considered her sole source of support.

Case 4: Nomsa

Nomsa is a 28-year-old part-time domestic worker with a grade 11 education. She lives with her husband, her six-year-old daughter (from a previous partner) and her adult niece in a 1-room shack. The household has access to a tap in their yard and a toilet outside the yard; they do not receive any material support; and are sometimes without food. Nomsa's husband is employed at a chemical factory.

Nomsa tested HIV positive three years previously, shortly after marrying her husband who also tested positive. She rated her physical wellbeing as good (7/10) and her CD4 count was 1 215 although she had been in hospital for two weeks in previous months. Her husband was receiving antiretroviral therapy and had applied for a disability grant due to periods of illness that prevented him from working. Nomsa was not yet attending a support group and described her husband as her main source of support. Apart from her husband, Nomsa had disclosed her HIV status to her niece a few months after diagnosis, to her brother-in-law two years after that, and to her sister-in-law more recently.

Case 5: Buyiswa

Buyiswa is a farmworker with a grade 9 education and lives in a one-room brick house with her mother, brother and six-year-old daughter. The house has both an inside tap and toilet. Buyiswa is 28 years old and has a partner who lives in her neighbourhood. Her brother is studying engineering, her daughter attends crèche, and her mother earns some income as a vendor. The household is rarely without food and receives no regular material support aside from Buyiswa's partner who contributes to their daughter's expenses.

Buyiswa tested HIV positive five years previously and had a CD4 count of 250. She felt physically well (7/10) and had not required hospitalisation recently. Her daughter, partner and mother were also living with HIV and none were receiving antiretroviral therapy. Buyiswa is only sometimes able to attend support groups (due to her work hours). She had disclosed her HIV status to her mother and partner immediately after diagnosis, and to her brother (that lives in the household) and aunt (who lives in the neighbourhood) three years later.

5.3 A NARRATIVE ANALYSIS

5.3.1 Disruptive experiences, chaos and loss in relation to HIV

There is often an implicit assumption that living with HIV is a source of disturbance, an idea consistent with a traditional psychiatric/mental health paradigm. With some notable exceptions (Garmezy & Masten, 1994; Luthar, Ciccheti, & Becker, 2000; Masten, 1994), this paradigm tends to focus on distress and disorder rather than resilience and healthy psychological adjustment. The parallel within the narrative perspective may be a corresponding expectation that narratives characterised by loss, disruption and even chaos would be dominant in the accounts of women living with HIV.

In general, the analysis suggested something different and more subtle. For one, the term biographical disruption (as used by Bury (1982)) while not irrelevant, appeared too broad and encompassing, suggesting a fairly radical shift that was not clearly evident for any of the women. Degrees of disruption and disturbance and chaotic moments were, however, narrated and lend themselves to the term 'disruptive experiences' rather than 'biographical disruption'. Moreover, these experiences tended to be linked to infection and diagnosis, as in Ciambrone's (2003) work with women in the US.

Two women had particularly difficult experiences related to diagnosis. For Pumza, this involved losing the partner who had infected her (but did not believe that he was infected himself) as well as several of her friends after disclosing her diagnosis. For Zoleka it meant losing her house and community after her common law partner died of AIDS (before she herself tested positive):

> Oh, when the man that I was staying with died, his family wanted to take everything that was in the house and it was this whole fight, they wanted to stab me. … what they actually wanted was the furniture that was inside especially the two refrigerators. The other thing was the house because the government was about to build brick houses. … They actually wanted me to leave with nothing, but I took everything overnight without them seeing. His brothers wanted me to stay, but their nephews were actually chasing me out. … They didn't care about him when he was still alive. … When he was dead they demanded everything (interview 3).

Subsequently, she experienced a marked loss of quality of life as she had to set up home in a new community without the resources and (relative) financial security that she had been accustomed to. It was during this time that Zoleka confirmed her positive status when she tested several months later.

For one of the other women, disruption was also associated with infection by her partner, although in a different set of circumstances. Nomsa was diagnosed shortly after her marriage and subsequent to her husband testing positive, and described feeling "shocked and upset" as well as confused as to how this could have happened (in what she experienced as a highly significant and trusting relationship). At the time, she also experienced a loss of certainty and a challenge to her expectations about the world, including her husband, and sought couples' counselling for depression. Initially, she "wouldn't even go to the shops. I would say that I don't need too many clothes after all I will die very soon" (interview 2). She thereby expressed what Frank (1995, p. 38) believes to be a question that virtually every person facing a serious disease asks, "'Why buy shoes? Why have dental work done?'" This moment in Nomsa's narrative, in addition to reflecting disruption, conveys the idea of lost desire for life and difficulty engaging with the future that Crossley defines as the story of loss. Nomsa's chaos is difficulty thinking about something other than being positive at the time, leaving her stuck and emotionally challenged or depressed (interview 3).

One of the other women also spoke of concerns regarding death at the time of diagnosis, reporting that "all she was thinking about was death and that HIV kills" (interview 3). Buyiswa was also the only woman to test positive during pregnancy or to have an HIV-infected child, and the youngest at age of diagnosis (23 years). Subsequent to her diagnosis, she disclosed her status to her mother who responded by not allowing Buyiswa to clean her clothes in the same bucket or hang her clothes on the same chair as the rest of the household. However, this situation eventually changed, most likely after Buyiswa's mother was diagnosed HIV positive herself.

For the remaining woman, it appeared that disruption was largely experienced in relation to events other than the diagnosis of HIV. Consequently the relevance of disruption as related to HIV specifically is less clear than in the case of the other four women. By Lindiwe's

account of her life, being diagnosed HIV positive had little impact since it post-dated two radical events/shifts in her life. Following her early and middle childhood during which she reported that "[e]verything was nice, I was growing like an egg, I was getting everything, there was no lack of anything I needed", "there was a quarrel" between Lindiwe's mother and father, they separated and things began to change for her (interview 1). She described having lots of boyfriends, smoking, drinking and being very "silly". However, "[a]t the age of twenty-two I accepted God and become very strong, but I was getting very sick" (interview 1). She was later diagnosed with TB and eventually HIV.

Therefore when Lindiwe "heard about this disease, I had already accepted God into my life" and was "not afraid for this disease. ... I told myself that I am going to live like the other people" and nothing changed (ibid). For Lindiwe it therefore appeared that her parent's separation and her later acceptance of God following a rebellious period, and not her HIV diagnosis, represented significant shifts in her life or experiences of rupture. The depth of this as a reading of her narrative will be challenged later (as part of the notion of the unspeakable). However, for the purpose of this comparison, it is important to draw attention to the ways in which Lindiwe's account differed from the other women's and that disruption can emerge in the life narratives of women living with HIV in ways unrelated to HIV diagnosis.

While the other women did report varyingly difficult experiences associated with diagnosis for which Bury's (1982) theory provided a useful analytical tool, these experiences were clearly time-limited and occurred in the context of a range of other life events that did not merit the term disruption. It is for this reason that the term 'disruptive experiences' is preferred to 'biographical disruption' that connotes a deep and substantive change in the individual with chronic illness. Further, while the theoretical fit between Bury's concept and Frank's and Crossley's narratives of chaos and loss was suggested, the experiences of these five women lend only limited empirical support to the relevance of the latter two concepts.

While Nomsa talked about a degree of chaos, but more particularly the kind of difficulty engaging with the future that Crossley refers to in her story of loss, the chaos narrative and story of loss were not reflected in the other women's HIV-related experiences. As the later

analysis will indicate, these were not women that were constantly emotionally overwhelmed (Frank) or that were living in an empty present (Crossley) as a result of their HIV status. The kind of biographical disruption that Ciambrone (2003) reported in her sample of North-American women is therefore not evident, nor the juncture to which Soskolne (2003) referred in her sample of South African women. At least where HIV was concerned, these women were therefore not "narrative wreck[s]", particularly beyond the time surrounding diagnosis.

This is not to suggest the failure of the chaos narrative or the story of loss, but rather that its relevance for these women must also be sought beyond diagnosis. An example is the case of Lindiwe, for whom her parent's separation and her acceptance of God were significant shifts in her life that predated and superceded receiving a positive diagnosis. Further, as later analysis will substantiate, it may be more useful to view chaos or disruption as a moment in a life that is otherwise experienced as continuous and without a marked challenge to temporality. It may be that the approach taken in the present research is more likely to draw attention to a range of life experiences than the lens of biographical disruption. In the current approach, disruption is an analytical tool in the context of a broader attempt to situate women's experiences of HIV. In addition, the combination of a narrative approach and a longitudinal research design facilitated a richness of understanding that examines, rather than assumes, the salience of HIV. Given this objective, it is important to further examine the relevance of chaos, loss and disruption in women's broader narratives as well as the relevant shifts and competing narratives. If women slip between and across different narratives, it is important to explore the context of these shifts. This may facilitate an understanding of the factors that underpin the various stories that women combine, alternate between or repeat, as Frank (1995) suggests.

5.3.2 Chaos beyond disruption and the untellable

Further exploring 'chaos' beyond its use in the above analysis, two cases in particular provide useful illustrative material and will be presented in some detail. One case will be used to illustrate chaos apart from HIV (similar to the example of Lindiwe given above) while the other deepens the reading of disruption already given through the use of the concept of an untellable unconscious. In both cases, aspects of Frank's (1995) chaos

narrative not found in the above will be drawn on. At the core of this construction of chaos is the idea that a physical or emotional wound is that about which an individual cannot literally speak, but must instead constantly remain at the edge of.

5.3.2.1 Chaos beyond HIV: The case of Pumza

The most powerful example of the chaos narrative is Pumza's account of her immediate financial difficulties, illustrating the salience of experiences other than living with HIV. After asking Pumza about her Christmas and New Year (during the final interview conducted in late January), at least ten minutes followed during which she attempted to communicate obvious distress at her inability to meet her financial obligations: "... everything depends to me, I can't manage everything and the money I have from the government is too little. I can't for my problems[51]" (interview 3). A few minutes into the interaction, during which "I can't manage" and "everything depends to me" became refrains that were repeated intermittently several times, she produced a shopping bag. The bag contained pages of letters and accounts to which she pointed and referred while continuing to try to articulate the details of her situation. These included: paying off a clothing account at a store that she was "living in fear" might arrest her; paying off a television that she had purchased for "the safety of my daughter because she stays to the neighbours the whole night [to watch television and these] days it's the bad days because people are kidnapping the daughters"; paying off a Hi-fi and fridge; buying food for herself and her daughter; and making her monthly rental payments. As she spoke about the fact that she had paid some money already, but was "still owing a lot", she began to cry quietly inbetween continued pointing and explanation regarding what she owed and could not pay at the end of that month. Pumza continued:

> So these are the things that stress me up because everything depends on me. I have even filed for child maintenance because the father of this child left me and ran to the Eastern Cape. Everything depends on me now. ... I can't manage, even me, like I haven't got like nothing, like clothes. Even me I can't manage to buy myself because the problem, I've got a child and she wants to eat, and my account also depend to me, everything and the rent also depend to me.

[51] This communication and some of the others included in this section were rendered in English and have therefore not been translated. Further, the grammatical expression used by the informant has been retained.

As the narrative was interrupted by the interviewer's questions regarding Pumza's coping strategies, the narrator became more coherent, at least for the listener. She said that she was "not managing because I do not have a job" and tried to "avoid stressing myself about this but it's difficult". Nonetheless, it is clear that before the shift brought about by questioning, Pumza's story was a good fit for Frank's (1995) chaos narrative. While some details of her experience were communicated, as was the emotion it evoked, the narrative lacks a coherent sequence, perpetually interrupting itself and conveying a clear sense of Pumza's feeling of being out of control, vulnerable and impotent in the face of circumstances. The refrains "I can't manage" and "everything depends on me" are both the substance of her narrative and that which interrupts its attempt at coherence and conventionality. The effect of repeating old details while adding new ones to her story is to create an "untellable silence [that] alternates with the insistent 'and then' repetitions" (Frank, 1995, pp. 99-100).

Also important is the effect of the narrative on its listeners, in this case the interviewer and the translator/interpreter who were present to participate in the telling. As noted above, Pumza's narrative became more coherent during the course of the interview. However, during the production of the above narrative, the interviewer was aware of both herself and the interpreter casting looks in each others' direction that suggested their difficulty fully grasping Pumza's meaning. Further, the effect of the narrative on the interviewer was evident in the subsequent decision to use available research funding at the time to purchase Pumza food stamps and the school stationery that her daughter needed. Such action was not part of the research protocol and was not taken with any of the other women interviewed despite the fact that they were all living in impoverished circumstances.

Thus the decision to intervene in this case strongly indicates the powerful emotion communicated by the narrative (Frank suggests that the chaos narrative is anxiety-provoking) despite the fact that the narrator could only really remain at the 'edge of the wound'. The existence of Pumza's 'wound' - what she verbalised as "stress" and "I can't manage" and enacted through her tearfulness - was thus confirmed by the response that it evoked. This is what psychoanalyst Melanie Klein terms projective identification – internalising and responding to a thought and belief that an individual unconsciously projected onto/communicated to another individual and that that individual in turn received.

5.3.2.2 The untellable chaos: The case of Lindiwe

In the second illustration, an additional and alternate reading of the relevance of chaos and disruption will be offered. The details of Lindiwe's narrative already presented (in section 4.2.2) indicated that being diagnosed HIV positive was not a disruptive event for her. In fact she reported that "nothing changed" since she had already accepted God and "was not afraid for this disease". This reading depended on taking Lindiwe's version of events at face value and drew only on an understanding that was either in her conscious awareness or that she was consciously willing to share at that moment in the interview (her first meeting with the interviewer and second with the interpreter). However, a closer analysis of Lindiwe's transcripts through the lens' of Hollway and Jefferson (2000) and Craib (2000) suggests that reliance on conscious communications and expressed emotional talk alone can sometimes lead to a superficial analysis.

According to Hollway and Jefferson (2000), a psychoanalytic approach to narrative is needed that acknowledges that people's actions (and verbal and non-verbal communications) are both consciously and unconsciously motivated and conflictual. People's talk is not necessarily transparent because the "psycho-social subject" cannot be assumed to "know[s] its own mind and ... communicate this in a largely autonomous fashion" (Hollway, 2001, p. 13).

Consistent with Hollway and Jefferson's position despite not using the term "unconscious", Craib's (2000) narratives of "bad faith" (Satré's term) involve various manifestations of the denial of psychological processes. Within psychoanalysis, the unconscious is the repository for material that an individual cannot tolerate being in their conscious awareness, including that which s/he defends against through the use of denial. According to Craib, bad faith can manifest as the displacement of emotions into 'unemotional talk' as well as the denial of the complexity, contradictoriness or disruptive strength of these feelings at times. Rather than referring to an unconscious, Craib (2000, pp. 69, 71) articulates his position

> that we have to look in two opposite directions at the same time - at the imaginary creativity with which people tell the story of their lives and at the reality of those lives - and also at the meaning of the difference. ... Sometimes people will express their emotions in ways in which they cannot recognise them as emotions.

Accordingly, an analysis that draws on Craib's contribution must move between that which women narrate – the 'creativity' of their stories – and their lived experience – the 'reality' of their lives – in order to fully explore their psychological experiences. The value of this position will be returned to again later in the analysis.

Turning first to Lindiwe's case, two important points emerged when situating her above-mentioned statements in the broader narrative. Both points suggest that she used language defensively at moments in the interview when questions challenged the coping strategies in which she was strongly invested at the time. Accordingly, an unconscious or bad faith process was at work.

In the first example, Lindiwe responded with a version of one of three refrains repeatedly during the first interview, always at moments when she was questioned about her childhood experiences or times in her life when she felt that she could not cope. These variations were: "I didn't have problems [while growing up]", "Everything was fine", and "Everything was very nice"; "I was not afraid for this disease", "I'm going to live like the other people", and "I don't describe myself like someone who is HIV, I describe myself like the other people"; and "God accepts you no matter who you are", I have "faith in God" and "I don't do other things [apart from abiding by her faith and attending church]". Second, having communicated effectively in English for most of the interview, Lindiwe chose to use the interpreter when asked to describe herself, when asked about difficult times that she had experienced in her life, and when asked to rank HIV in terms of its overall salience and importance in her life. At the very least, this response set reflects the lack of complexity which Craib (2000) refers to as one of the manifestations of emotional denial.

Seen in isolation, it might be inappropriate to assume that these statements were used defensively. This is particularly true since a research interview cannot be equated with a thorough clinical assessment which provides the detailed history and formulation needed to

interpret communications in this manner. However, not only is there objective evidence that Lindiwe's communications were expressed repeatedly and at very particular moments in the interview, they evoked a sense of their real importance in the interviewer and interpreter, as well as creating confusion, frustration and uncertainty. There was also additional evidence to challenge the likelihood that "everything was fine" during Lindiwe's childhood and that her HIV status was in no way a disruption in her life. With regard to her childhood, Lindiwe reported during the last interview that her mother used to drink too much and shout at her, suggesting that statements that "everything was fine" are probably at least a partial idealisation of her childhood. This view was substantiated during a home visit made by the interpreter/research assistant (since Lindiwe was too ill to travel to the clinic to be interviewed) where Lindiwe's mother was observed drinking alcohol during the late morning. Lindiwe also offered evidence of other negative life events that she had kept "secret", namely the fact that "two guys raped me", saying that "you are the first person to tell you this" (interview 1). With regard to Lindiwe's position on her HIV status at the time, her verbal protestations stood in marked contrast to her repeated coughing throughout the interview, a symptom of her chronic TB and her HIV. The idea that her coughing symbolised the disruptive insertion of HIV into her narrative despite her statements to the contrary was confirmed later by the sudden deterioration of her health that resulted in hospitalisation and diagnosis with full-blown AIDS.

Taken together, this evidence indicated Lindiwe's unconscious need to present herself as coping, either through denial that HIV was a source of disruption or through the use of language (not spoken by the interviewer) to distance herself from personal questions that she felt too threatened to answer directly or honestly. The gap created between herself and the interviewer/question by her confusion understanding English and the need to have the question translated into isiXhosa therefore aided Lindiwe in protecting the coping self that she needed to preserve from the potentially bad feelings that the questions might evoke.

It is possible that the idealisation of her childhood functioned in the same manner, splitting off bad associations, memories and experiences from her view of 'everything as fine' that she needed to preserve. The effect of this denial and idealisation is that Lindiwe's early narrative leaves HIV the unspoken wound at the centre, just as Pumza's narrative circled at the edge of her distress (Frank, 1995). During the first interview, when Lindiwe was in

poor physical health, HIV was added to a list of untellables in her life, in particular the fact that she had been raped and had lived with an alcoholic mother. What is significant at this point in the analysis is that the idea of the untellable unconscious contributed to a richer understanding of Lindiwe's narrative in which "chaos" and "disruption" in relation to HIV had previously seemed irrelevant. The fact that this coping strategy was employed at a time when she was in a poor state of health will be returned to later in the analysis.

5.3.2.3 The contribution of context and culture to unemotional talk

Before proceeding to discuss the factors that underpin shifts in and out of chaos for HIV-infected women more explicitly, some other interpretive possibilities regarding the absence of emotional talk must be considered. The psychoanalytic explanation that women are invested in warding off unconscious anxiety evoked by their HIV status and other difficult life experiences has already been presented, and Lindiwe's narrative (in her first interview) argued to be a particularly clear example. However, at least two other possibilities exist.

First, the potential role of barriers created by language and the need for translation cannot be ignored. Every attempt was made to draw on a verbatim translation of the women's responses, both during the conducting and transcription of interviews. Further, as noted in Chapter 3, the same person was used to translate and transcribe in order to enhance the validity of the transcripts. However, there is an inevitable gap in understanding created during translation in addition to the cultural barrier that translation must attempt to transcend given the very different socio-cultural positioning of interviewer and interviewees. Not only was difference in language literally a barrier to understanding, language is an expression of culture and culture a mediator of the expression and form that mental health takes (Patel, 2001; Patel, Abas, Broadhead, Todd, & Reeler, 2001; Swartz, 1998). Thus it is possible that some emotional talk was missed by the interviewer during the interview or by the transcriber during transcription, or that is was simply lost in translation due to the gap between an utterance and its translation.

Second, it may be that the "sense of need for a personal voice depends on the availability of the means – the rhetorical tools and cultural legitimacy – for expressing this voice" (Frank, 1995, p. 7; see Bruner, 1991 for a similar argument). In the context of the present

analysis, women required a voice for their emotional experiences and vulnerability, and perhaps this was a kind of talk that was unfamiliar and that did not fit their expectations about what was permitted in a clinic setting (where the interviews were conducted). None of the five participating women had had more than a few sessions of directive counselling and none had ever participated in research that gave them the opportunity to be interviewed in an open-ended manner. It is thus quite possible that their life experiences had done little to provide them with the rhetorical tools to engage in emotionally expressive talk, particularly with individuals that they did not know.

The fact that this talk also lacked cultural legitimacy in a medicalised setting is further suggested by an experience that Pumza reported. In response to the interviewer's statement that she "hope it helped that there was someone that you could share your problems with", Pumza responded:

> Yes, it helped. Like I always tell myself that it's better to come to the clinic with your problems, but sometimes it's not always easy to talk to the nurses. They would remind you about the fact that you have a [disability] grant. They do not know that your problems are bigger than this grant.

Despite Pumza's apparent openness to share and be vulnerable, she found that the medical setting either silenced or could not hear her concerns. Nurses, who constitute the frontline of public HIV services in South Africa and much of the developed world, are mostly accustomed to hearing stories about physical symptoms, CD4 counts, medication side-effects, appointment times, disclosure and support group attendance - the tropes of public HIV discourse. And a complaint about difficulties managing on a disability grant was not one of these tropes.

However, after two lengthy individual interviews, Pumza was able to share these financial concerns in some detail with the interviewer (as discussed earlier in this section). This indicates that the interviews, despite being conducted in a medical setting, eventually provided a space within which at least some of the women could differentiate the research interview from its medical context and develop the rhetorical tools to express themselves (in a manner required during an interview). Another concrete manifestation of this was the deepening of rapport that was experienced to a degree with all the women over the six-

month period that interviews took place. This was most apparent at the final interviews during which many personal details were shared by the women, for example, Nomsa's previously undisclosed relationship difficulties with her husband and a detailed account of Pumza's relationship with her ex-partner who she said had "always been an abusive person".

5.3.3 Alternatives to chaos or what happens inbetween: conversion, normalising and the competing narratives

The above analysis has already begun to suggest that HIV-related chaos and disruption is an incomplete approach to understanding the experiences of HIV-infected women living in poverty. However, two other illness narratives must still be considered: the restitution narrative or normalising or external story, and the quest narrative or the growth or conversion story (Crossley, 2000; Frank, 1995).

5.3.3.1 The quest/conversion narrative

With regard to the quest/conversion narrative, the women did not describe themselves directly as having experienced personal growth (Crossley), or confronted their disease "head on" as part of a personal journey (Frank). However, there is evidence in two cases of women using aspects of their HIV-related experience in order to educate, support or encourage other community members. This suggests that some kind of internal shift had likely occurred.

For example, Pumza referred to her willingness to speak to other people living with HIV in order to support and encourage them:

> ... Then I started to attend the support group; that's when I got the courage to talk about HIV to people and tell them I am positive. When people have problems they feel free to come to me. Like the woman I was telling you about who lives close by. ... Even in the community, people come to me when they have problems ... (interview 3).

Having reached a degree of acceptance regarding her HIV status, Pumza was able to use her personal change to attempt to empower other women in her community. At that stage, she had been living with HIV for approximately five years herself and had been on HAART for more than six months. While Buyiswa also gave an example of speaking to a female colleague (a fellow farmworker) about her own HIV status and the need to seek treatment, this was an isolated incident and will therefore not be discussed further as a quest/conversion narrative (interview 3).

Similar to Pumza, Lindiwe described her influence amongst fellow church members with whom she had evangelised about the role of faith in her improved health:

> They [church members] say that I am a strong woman. My faith is reviving their faith because many people, when they hear that they are HIV positive and they are in stage four, they give up and lose hope, they stop trusting God. I assure them that they must have faith in Jesus… (interview 3).

Consequently, Lindiwe wanted to

> … strengthen the people with HIV. To tell them that when you have HIV you must live like other people. And to open their eyes that nothing is impossible to God, they must just trust in him. … I'm not afraid to tell people [about God]. … [I'll] go to the whole world and tell the people that God can make the impossible happen to me. That's what I want to do (interview 3).

From being "very, very sick; I couldn't talk, I couldn't eat, I couldn't walk", Lindiwe was eventually hospitalised and started on antiretroviral therapy, and was visibly strengthened after only two weeks (according to both her account and that of the research assistant who had made a home visit while Lindiwe was at her most ill) (interview 3). What appeared at the early stage of treatment to be her 'resurrection', thus evoked in Lindiwe a strong conviction to spread her belief in the "power of God" to work in the lives of people with HIV *and* AIDS (interview 3).

A qualifying note must, however, be made regarding this narrative. For one, Lindiwe was not as open about her HIV status in the church as the first quotation might suggest. She had not in fact openly discussed her status with anyone other than the minister who had counselled her. Other church members simply knew Lindiwe's HIV status since she

continued to attend church and "people can see. No matter you don't say it, but people can see … my face was just skin and bones" (interview 3). Thus while her narrative fulfils the requirements of purpose and personal growth, it is not explicitly linked with *her* HIV status in the way that a quest narrative would typically be. While Lindiwe could continue to evangelise (akin to what Frank terms testimony), the fact that she was not open about her HIV status like Pumza means that she will not become "a witness [who] assumes responsibility for telling what happened" (Frank, 1995, p. 137). To truly witness and tell what happened requires an openness about personal experience, and Lindiwe was not completely open despite claiming that "there is no need to hide it [being HIV positive]" (interview 3). Whether or not this is a contradiction in her narrative, it is certainly ironic that the many visible physical markers of her advanced illness had literally allowed others to witness her HIV status for some time already despite her silence.

5.3.3.2 Restitution, normalising and the anti-restitution narrative

As discussed earlier, Frank's restitution narrative is a story about health and becoming healthy again in which "the present illness is an aberration, a blip in the otherwise normal passage of time" (Frank, 1995, p. 90). There is therefore an attempt to gloss over the illness experience or at least to reverse its impact so that the individual returns to "normal". Similarly, in the normalising or external story, the individual is unable to face the possibility of death and therefore minimises the impact of a positive HIV diagnosis on his/her life and future plans (Crossley, 2000).

As with the quest or conversion story, these narratives do not provide a good general fit for the kind of stories told by the five women. Neither Buyiswa, Pumza, Zoleka nor Nomsa denied their HIV status or attempted to normalise or minimise its importance. In fact Buyiswa said that "death and that HIV kills" was all she could think about after her diagnosis, while Nomsa believed that she would "die very soon". Although their responses are clearly rooted in fear, they nonetheless involve an engagement with HIV status and there is no later evidence of attempts to undo and return to "normal".

In contrast, however, Lindiwe's narrative does tell the normalising story in parts, for some of the same reasons that it was read as conveying the untellable in Frank's chaos narrative.

Read through the lens of the restitution or normalising narratives, Lindiwe's refrains in the first interview that "nothing had changed" since her diagnosis, could also be an attempt to normalise her experience through denying the impact of the disease. Lindiwe coughed repeatedly throughout the interview, and reported (during the quantitative study) having been hospitalised for three out of the previous six months. She also rated her physical wellbeing at two out of ten, lower than any of the 180 women interviewed. There was therefore objective evidence that Lindiwe employed denial, or minimised and normalised her experience at times, particularly during the first semi-structured interview in which she participated.

By Lindiwe's final interview, however, it was clear that a shift had occurred and that her narrative no longer employed normalising or minimising. Aside from her continued lack of clarity and openness regarding disclosure (as discussed above in the previous section, 4.2.4.1), she presented as fairly articulate and spoke openly about her illness and the need to confront it during the preceding two months. It was during this period that she was hospitalised and started antiretroviral therapy. However, what is especially important to note is her attitude toward death and its relationship to HIV:

Interviewer: And what did you feel when they [the doctors] told you they were going to put you on ARVs?
Lindiwe: I ask for myself.
Interviewer: No-one mentioned it to you?
Lindiwe: No, I asked because I could see that the tablets that they gave me didn't help me at all, so I asked because I could see that I was dying, and I heard from people that 'go and take ARVs, you will be better then'. When I was in … [Hospital], I asked the doctor, 'please doctor, please doctor go and check my CD4 count' and it was 140, so they put me on ARVs immediately.

In contrast with her previous denial and minimising during a period of less serious illness, Lindiwe openly stated that she was dying, and confronted the reality by asserting herself and advocating for her right to be put on antiretrovirals. It was following this experience that she began evangelising in order to "strengthen the people with HIV". Thus it seems that acceptance and confronting death – an anti-restitution narrative – facilitated the possibility of a quest (narrative), albeit one in which Lindiwe's guardedness regarding disclosure preventing open witnessing.

5.3.3.3 The nature and salience of HIV: Competing narratives

What is striking at this point in the analysis is that all three narrative types are told in Lindiwe's story. In contrast, Buyiswa, Nomsa and Zoleka's narratives contained only elements of disruption associated with diagnosis, while Pumza's narrative contained both disruption and quest/conversion. Further, while chaos was relevant to Pumza's narrative, it was in relation to her financial situation rather than her HIV status.

An examination of this finding points to two related issues in particular: one concerns the salience of HIV in relation to other contextual factors in women's lives, while the other concerns the nature of HIV as a fluctuating condition with different disease stages.

Being sick versus having an illness: HIV, AIDS and HAART

Lindiwe, the women whose story includes all three narrative types at various moments, is also the woman who was most ill and who commenced HAART during the course of the study (see sections 5.3.2.2 and 5.3.3.2). While it may seem banal to conclude that illness narratives were most frequently told in the narrative of the one woman who was actively ill, this is a point that is often missed in research with HIV. One example of this is the failure of certain quantitative studies to analyse the role of disease severity (as opposed to HIV status per se) in predicting individual outcomes (see Chapter 2, section 2.2.2 for some exceptions; Brandt, 2005b).

Lindiwe was symptomatic and incapacitated throughout the course of the study, and it was this that drew 'illness' into her narrative rather than her HIV status per se. This was clearest during the home visit and the final interview (at the clinic) conducted after her hospitalisation, when illness occupied a very substantial part of the interviews. This was in contrast with the first meeting during which she was invested in downplaying the relevance of HIV.

While HIV/AIDS is often used as one term, it does not refer to one thing; rather AIDS is an advanced stage of HIV infection associated with more serious illness for longer periods of time. During earlier stages of infection, periods of illness are intermittent and less acute

and debilitating, and it is understandable that women were less likely to view themselves as ill and hence to include narratives of illness and HIV in their stories. Moreover, for women on HAART, particularly those who have been on treatment for a substantial period of time, their experience of the disease may once again begin to approximate the earlier, asymptomatic stages (despite the fact that the diagnosis of AIDS is retained[52]). Differentiating women according to both stage of disease and access to and duration of antiretroviral treatment is therefore important.

Contrasting Lindiwe's health and HIV-related history with those of the other women, it is evident that all four women were in relatively good health at the time of the study despite their positive HIV status. For two of the women this was due to the early stage of their disease, while the other two had responded well to antiretroviral treatment. Nomsa's CD4 count was especially high at 1 215 (the highest of the 180 women in the study) while Buyiswa was not and had never been sickly: "I'm not a sickly person, I do get tired from time to time but it has never been anything serious ... I'm never seriously ill" (interview 3). In the case of the other two women, Pumza's CD4 count had improved from below 200 to 415, allowing her to recommence her usual daily functioning, and Zoleka reported that she "last felt this healthy before I got this problem [HIV]". She had even gained enough weight to be "back to the clothes I haven't worn in a long time because they were big [due to illness-related weight loss]" (interview 3). Both access to treatment and disease severity were therefore important factors moderating the salience of illness narratives in the women's stories.

A caution must, however, be added regarding the experience of disease. While the above narratives point largely to the relevance of illness and HIV narratives where women are objectively ill (in the symptomatic stage of disease), there are other possibilities which are also important despite emerging less clearly in the analysis. For example, some women will experience themselves, subjectively, as more ill than another woman with the same disease parameters, with more adverse implications for her psychological wellbeing. This is corroborated by research evidence that subjective disease parameters are better

[52] According to the South African treatment protocol, the medical criteria for patients commencing HAART is that they must either be classified as having WHO stage 4 disease (AIDS) or have a CD4 count of less than 200 if in stages 1, 2 or 3 (Department of Health, 2004). However, as patients respond to treatment and their CD4 count increases, their disease is not re-staged. Consequently, it is possible for an individual on HAART to have a clinical diagnosis of AIDS despite having a CD4 count of over 200.

predictors of infected women's mental health outcomes than objective laboratory markers (a finding confirmed in the present analysis reported in Chapter 4) (Jones et al., 2001; Rabkin et al., 2000). Of course, it is the ambit of quantitative, rather than qualitative research to differentiate objective from subjective experience, hence it is appropriate within the present chapter to merely draw attention to this issue.

Context and the position of HIV in the hierarchy

The second point regarding how illness narratives emerged across the five cases, concerns the salience of HIV in women's lives. Not only were the women for whom illness narratives were less prominent less ill, they also tended to experience other contextual factors as more salient, and even urgent.

For some of the women, issues related to mothering were important. During the course of the study, the number of dependants for whom Zoleka was caring increased from four to five, when a niece unexpectedly arrived in Cape Town to join her. At the time, she was already living with and caring for her two teenage daughters and their two infant children. Given her limited resources – she had no regular income at the first meeting – this was a potentially difficult situation. Nonetheless, Zoleka's response to her niece's arrival was to say that "it is exciting because I never had like a lot of children I only managed to have two and now that the house is full I must work hard to feed them" (interview 3). Although she was clearly aware of the likely difficulties involved in having "to feed them", this was nonetheless a salient and important aspect of her life. Several other parts of her story also related to concern for her family. For example, the fact that her eighteen-month-old grandchild was present during the second interview since she had taken responsibility for his care, and her desire to send her fourteen-year-old daughter back to school since she was "a bright kid" who had left school after falling pregnant (interview 3).

Pumza also demonstrated concern for her child's wellbeing when she put herself in further debt in order to buy a television since her daughter was watching television at night at their neighbours and "it's the bad days because people are kidnapping the daughters" (interview 3). Despite the obvious financial implications (as with the addition of Zoleka's niece to her

household), Pumza believed that she was ensuring the "safety of my daughter", that being her primary concern.

Nomsa was similarly concerned with mothering; although in her case the issue was her desire to have a child with her husband (she already had a daughter from a previous relationship). This desire punctuated each of the three interviews and was clearly something with which she was greatly preoccupied. Nomsa was awaiting a doctor's appointment following an ectopic pregnancy and had already received counselling from a social worker regarding the implications of pregnancy for a woman living with HIV. Nomsa had thus taken the time to inform herself and felt strongly that she "would like to have even just one child" (interview 2).

However, while mothering was an important narrative for these women, the most dominant competing narratives across the five cases contained reference to women and their household's socio-economic situation. In addition, two of the three above narratives, while most explicitly concerned with mothering, were also linked to socio-economic issues. Financial pressures emerged as a narrative for each of the five women at some point during the interview process. However, Zoleka's comments are particularly apt in this regard:

> HIV has never been a problem to me. My major problem has always been finances. There were times when I couldn't even afford bath soap; I didn't even have clothes to wear. Things have gotten better now because I have a [disability] grant; the only thing I would like to have now is a job (interview 3).

Buyiswa and Nomsa similarly expressed the importance of employment, stating that: "if only I could have a good job, I would get myself out of these poor conditions" (Buyiswa, interview 3); and "if I could only have a job, my dreams will come true" (Nomsa, interview 3). Pumza, who had a physical disability that further limited her opportunities for employment (she suffered nerve damage to her right hand after being stabbed by her ex-partner) also highlighted the importance of employment: "If I could at least get a job. … I worry about these things a lot because at least if I had a job, I would manage to attend to some of my [financial] problems even if I don't solve all of them" (interview 3).

Pumza and Zoleka also explicitly linked socio-economic status to emotional wellbeing, further suggesting its importance over and above HIV in their lives:

> No, I'm very happy now that I got the money because I was ill and suffering, but I don't want to say that I am suffering now. Even the children are much better (Zoleka, interview 2).

> I don't know how I'm surviving. I try to avoid stressing myself about this [her debts], but it's difficult. ... I still have headaches. ... The Xhosas say when you are going through difficult times you end up having all sorts of pain [referring to pain in her legs] (Pumza, interview 3).

While being diagnosed HIV positive might result in a transitory preoccupation with death and even the loss of relationships, poverty and the "suffering", "stress", "headaches" and "pain" it can cause are more long-standing problems. And it was poverty through which these women's experience of life, including an HIV diagnosis, seemed to be continually filtered. The "problems" to which women referred most often as causing "difficulties" for them, their families and household members were financial ones. As Zoleka says, "I have no worries now. The only time I struggled was before I could get this money; when I lived on handouts from other people or come to the clinic for food parcels" (interview 2). This is consistent with the findings from a World Bank study that people living in poverty across the world frequently raise aspects of mental distress when discussing the effects of poverty (Narayan, Patel, Schafft, Rademacher, & Koch-Schulte, 2000). For both Pumza and Zoleka, suffering and stress were related to the difficulty of surviving without a regular, sufficient income.

While some of the complexity of these narratives will be highlighted later, it is noteworthy that an attempt to articulate a kind of "grand narrative" that best follows the storylines of women's lived experience inevitably returns to the fact that these were women living in poverty. Context, and this aspect of their context specifically, was therefore essential in understanding women's life experiences, suggesting the deeply situated nature of narrative. Living in poverty and dealing with its associated stressors was 'normal' for these women and it is within this context that the reduced salience of HIV must be understood. For such women, HIV was generally in the background rather than the foreground. Further, HIV

was drawn in at times when it gave rise to disruption, chaos or growth, and often, although not always, when women were actively ill.

5.3.4 A different kind of restitution and the role of contradiction

5.3.4.1 Poverty, normalising and HIV

The idea of an illness narrative for HIV-infected women living in poverty has already been called into question for two reasons in particular. First, women with HIV are not always ill (either objectively or subjectively), particularly where HAART is an available resource, and second, factors other than disease may be salient in women's lives, including their financial situation. That said, it may be instructive to return to the restitution/normalising narrative outlined earlier in order to reframe its relevance.

It was argued that, for at least four of the five women, restitution had limited applicability since their stories were not concerned with health and illness and they did not make overt attempts to minimise the reality of diagnosis and its impact on their lives. However, perhaps a more differentiated consideration of restitution is appropriate in light of the role of context suggested above. It is true that women spoke about HIV not being important or high on the list when asked about its position in the hierarchy of significant issues in their lives. Nomsa and Lindiwe, for example, responded in the following manner:

> Yes, HIV it's just one of the things in my life, but I wouldn't put it on top of the list and I told myself I'm not going to die. I know I'll die one day, any other person can die, but I told myself that it's an illness and I'm not the only one who has it, a lot of people have it… (Nomsa, interview 2).
>
> It's something that is not important (Nomsa, interview 3).
>
> I don't describe myself as someone with HIV; I describe myself like the other people. … It would be at the bottom [of the list] (Lindiwe, interview 1).

Further, certain of the women articulated a future orientation, some in general conversation and some in response to a specific question. This might be interpreted as living in the future and therefore consistent with Crossley's normalising/external story. Lindiwe opened

a savings account at the post office just as soon as she began receiving her disability grant and was able to start working as a vendor and saving money. Further, she planned to use this money to send her youngest daughter back to school and by the time of the last interview, had been successful in executing this plan despite losing her daughter's most recent school report, a barrier to entry in many South African schools. Pumza and Nomsa also spoke of an imagined future and future plans. Pumza stated that, "It's important that I plan and that I do have money put aside in something like '60 bonds' for my child" (interview 2), while Nomsa was planning to have a baby and clearly "wanted to live longer": "I just want to enjoy life with other people, my siblings, for example. ... There is a lot I would like to do if I succeed. That is why I want to get a job" (interview 3).

The above quotations from the women's interviews might be seen to suggest that they lived in the future and minimised the impact of HIV on their lives (saying that it was not important). However, examining other requirements of the restitution narrative, these were not women whose stories were preoccupied with health and illness. Rather, given the freedom to choose when and how to enter HIV or AIDS into their narratives, many women spoke of other issues first and Nomsa referred to her husband's HIV positive status before her own. Further, (as suggested in 5.3.2.3) as the study progressed and rapport was built, the women spoke more freely about other life experiences, providing a fuller context and a broader lens within which to consider the salience of HIV in their personal lives. Access to HAART promised and was even delivering a reversal to good health for some women (at the final interview, Lindiwe had just commenced treatment, and Zoleka and Pumza had been on treatment for six and 12 months respectively). However, rather than returning to "normal", women's narratives as a whole convey a sense of continuity and sameness.

Many shifts and changes occurred, some of which have already been referred to. Zoleka's daughter started and ended a piecemeal job, and recommenced school; Zoleka and Nomsa's husband began receiving disability grants; Buyiswa moved away from the home of her family of origin to live closer to her work and reduce her transport costs, and later moved back when alternate arrangements could be made; Buyiswa's mother began another job as a domestic worker, increasing the household's income; and Nomsa's daughter began living with her grandmother nearby which she apparently preferred because "there are a lot of kids there" and so she gets less "bored" than at home (interview 3).

However, these shifts were experienced as interwoven in women and their households and families' daily lives, as part of the typical ebb and flow. As much as things changed, they also stayed the same, and perhaps this was most profoundly about the level of poverty in which these women had spent their lives. This is perhaps what Miliband meant when he referred to poverty as "an atmosphere in which large numbers of people live their lives and which threatens at any time to assume a more concrete presence" (Miliband, 1974 in Levetan, 1984 in Wilson & Ramphele, 1989, p. 185). Zoleka had grown up on a farm in the Eastern Cape in what was likely a very low resource area, while as an adult she experienced times when she "couldn't even afford bath soap" (interview 3). Similarly, Pumza described a time when she "did not have anything at home. We lived on left over bread that used to be delivered from shops like Pick 'n Pay. Sometimes it was stale but we had to eat it. ... That bread would last you that moment, after that you have nothing...." Moreover, the one-room shack in which she lived with three children and one other adult was made of "material [that] is rotten and starting to fall off; it's extremely tiny. The place is dusty, not suitable for a sick person, but I have no choice" (interview 3).

To draw on Peel's term, originally used in reference to traditional African religious systems, the women's orientation expressed in their narratives is therefore predominantly 'this-wordly', concerned with "time-space-events" as opposed to the future (or an after-life) (Peel, 1968 in West, 1975). As already demonstrated, this did not mean that women were incapable of thinking about and planning for the future, but rather that their narratives convey a sense of *living* in the *present* and not the future as the restitution narrative suggests. The 'present' placed many demands on women and thus it is not illogical to suggest that they were not necessarily minimising the relevance of health and illness when noting its relative lack of importance. Rather this could be interpreted as a legitimate contextualising of HIV in a life that is genuinely larger than a disease.

The position that the remainder of the analysis will develop is that it is not either or: both minimising and contextualising may occur in one narrative, as might other seemingly contradictory positions. Thus while poverty has been argued to provide the substance for a kind of "grand narrative" or underlying story, the women's stories constantly confront one with the difficulty of separating poverty and HIV/AIDS.

5.3.4.2 Coping with poverty and HIV: Contradictions in marginalising HIV

The important critique of restitution/the normalising story is that sometimes the relative lack of importance of HIV for these women was simply a function of context. However, at other times, they may also have needed to minimise or distract themselves from the reality of their lives, including their HIV status. Data gathered as part of the quantitative study (through the administration of a standardised measure) indicated that self-distraction was one of the more frequently used coping strategies amongst the five women. Further, Pumza referred to the inability to distract oneself as something undesirable during the case study interviews:

> Yes, I do miss the [support] group because when I'm there I forget about all these problems. But the minute I come home I'll start thinking about the fact that I have all these problems and I need to solve them. They won't just disappear (interview 2).

Just as contextualising has been shown to be a legitimate narrative reading, so too is women's reported attempts to employ self-distraction in order to manage or reduce anxiety and distress (Lazarus et al., 1984). Focusing one's attention on poverty may even serve as a useful form of self-distraction at times, protecting women from untellable experiences associated with living with HIV.

Other coping strategies that have the same potential outcome (whether intended or not) are women's acceptance[53] of their HIV status and their characterisation of HIV. Both can moderate emotional difficulties that women might experience in a given situation, allowing them to continue their lives in the absence of debilitating distress. With regard to the latter, Zoleka's narrative captures the manner in which women characterised HIV in their narratives:

> When I heard that I've got it, I did not worry myself at all, I just told myself that everybody has got it, the person who does not have it is the one who has not tested. Even here [the clinic] you see that it's full; everyone has got this. Even older people, they can be your mother's age, but they have it (interview 3).

[53] During the factor analysis conducted on data from the Brief COPE (see section 3.3.3.2), Carver's original subscale of self-distraction and one of the two items from the acceptance subscale loaded on one factor, suggesting a commonality in the way in which they functioned in the participant's responses.

With regard to acceptance, all women referred to acceptance of their status in some manner during the interviews, either directly or indirectly. Zoleka stated that she had accepted her HIV status because she could not change the situation and must therefore learn to live with it (interview 1), while Buyiswa "believes that she wouldn't be bothered [about this thing of people calling other's names in the street] ... because she is opened about HIV" (interview 3). Just as acceptance allowed women to "live with it [HIV]", characterising HIV as a common illness that "everybody has" served to distract women from the fear and depression associated with other characterisations of HIV, for example, that "HIV kills" (see section 5.3.1). If believing that HIV kills is associated with fear, depression and impotence, then reframing HIV in a less threatening manner as a disease that other people have and are living with might have the effect of reducing distress.

Such strategies, what Lazarus and Folkman (1984) term "denial-like processes", are less likely to be effective in later stages of a potential crisis situation. While it is feasible, and even constructive, to employ distraction or reframing in the earlier stages of HIV or when HAART has resulted in improved health, this is not true of having AIDS. This is evident in the case of Lindiwe who shifted to accepting the possibility of death when her illness reached the most advanced stage (before the final interview). More so than the other women, Lindiwe began the study invested in maintaining the construction of herself and her family as "fine", and repeatedly stated that HIV lacked relevance and that she would not die (see section 5.3.2.2). However, she later expressed a more differentiated and less polarised (black and white) perspective.

In the final interview, Lindiwe referred to her household's financial situation as "a little bit good" and admitted that her mother had a drinking problem and used to shout when drunk (interview 3), Further, she reported that "I could see that I was dying" and said that "Even when the doctors told me I was in stage four ... I just said 'My God, it will be done, you are going to call me with this disease but if it's not your will, nothing will happen'". The transition away from denial-like processes in the advanced stage of disease is an important one that the other women had not yet been confronted with, given their comparatively good health. However, what is important at this point is that all of these coping strategies may have been necessary at times in order for women to keep HIV in the margins and thereby preserve their sense of emotional wellbeing.

Keeping HIV in the margins was nonetheless a difficult task as the presence of contradiction in women's narratives suggests (Soskolne et al., 2004). As already demonstrated, many women described HIV as something that was 'low on their list', suggesting its lack of salience and implications for their lives and emotional wellbeing. However, they also referred to the fact that HIV is "forever", to the visibility of the disease, and to the special needs of HIV-infected women, all of which contradict the construction of HIV as marginal.

On the first point, Pumza refers to HIV in the following manner:

> I heard it from the radio .... The people who deal with financial issues were saying HIV is not a disability. My point is it is a blood disability. It is forever, you are going to be buried with it. ARVs are not a cure; they only make you feel better. As Manto said it, there is no cure for HIV. So it's forever; it's something that I will take to my grave... (interview 3).

On the second point, women referred to the visible markers of HIV[54] that challenged attempts to marginalise it, particularly since visibility contributed to stigma. As Lindiwe stated, "it's easy to see a person with HIV. ... once you become thin, people will think that it's HIV; once your face turns dark, people will think it's HIV. If you just sick with something else, people will just think you are HIV. Even when you are coughing..." (interview 3). Moreover, this led to women being "scared that people are actually staring at me because I have this illness [HIV]" (Zoleka, interview 3). However, worse than the fear of being stared at, was the fear of what other people would say or do, "because people take it differently when you disclose to them, as if you are giving them a reason to insult you about it. ... if I tell other people they'll start talking about me, making me a laughing stock, forgetting that they might be having it themselves" (Zoleka, interview 3).

While not many women related experiences of stigma, they evidenced obvious caution in disclosing their HIV status, attributing non-disclosure to attempts to avoid stigmatising behaviour and attitudes. In Buyiswa's case, she differentiated between rural and urban relatives, stating that those in the rural areas lacked information and "would think 'oh no, she's brought this killer disease, we are all going to die' and they would spread the news

[54] See also section 5.3.3.1.

around. ... The whole village would know about my status. ... They wouldn't share spoons or dishes with me all those things" (interview 3). In the case of Pumza, anticipated stigma was realised when she disclosed to her then partner, at the insistence of clinic staff. As a result he "would stand outside and shout at me for everyone to hear ... he would insult me about AIDS, he would go places ... and tell his people that I have AIDS (interview 3). Anticipating the kinds of consequences experienced by Pumza, the women disclosed either selectively and deliberately or, in some cases, not at all.

On the third point, (when specifically questioned) some of the same women expressed the opinion that infected women living in poverty had needs over and above those of non-infected women in their communities:

> I think we have completely different needs as HIV positive people. First of all the diet is totally different, for example, we can't have acidic beverages, things like sugar, we can't have as much as we would like. So I believe that the main important need for HIV positive people is good diet (Buyiswa, interview 3).
>
> As a person with all these problems that I have told you about, I would really like to see more job opportunities ... We [women living with HIV] cannot rely on the grant because it could be taken away any time; it's not forever (Pumza, interview 3).

While Zoleka refered to the needs of both HIV positive and HIV negative women for "hygienic homes not dirty shacks" (interview 3), the other women believed that PLWHA have additional or more urgent needs. Poverty and lack of employment is a problem for the entire community in which these women live. Nonetheless, Buyiswa believed that diet was of greater importance for HIV-infected people and Pumza that job opportunities were more urgent given the prospect of infected people losing their disability grant.

What is particularly interesting is that all three women inadvertently referred to an interaction between poverty and HIV, even while attempting to articulate their opinion on the relative importance of poverty and HIV. Thus while some of the women expressed the belief that it was possible to differentiate between HIV and poverty, their narratives repeatedly betrayed an interrelationship.

There are several instances of this interaction in women's narratives. For one, women spoke of inadequate food (as Buyiswa suggested above) and poor housing conditions threatening the ability of HIV-infected women to take proper care of themselves. Pumza and Zoleka were quoted earlier stating that "dirty shacks" are "not suitable for sick people"[55]. For women on HAART, inadequate finances to ensure good nutrition have an added dimension:

> I spent four days not taking the medication [after the tablets were dispensed] because I was scared to take it. … I feared that if you do not eat proper food, it's [the ARVs] also going to affect you. The fifth day I managed to get proper food so I said 'oh, since the food was there, let me get my medication' (Zoleka, interview 2).

While good food is important for all PLWHA (or any other serious or chronic illness), Zoleka recognised the added importance for those taking antiretroviral treatment. By increasing the likelihood of inadequate nutrition, poverty thus has the potential to undermine the physical wellbeing of PLWHA as well treatment adherence and outcomes.

Second, women referred to the fact that HIV status might threaten job security or limit job opportunities. Nomsa reported that "there are jobs where they demand that you do an HIV test before, so that limits chances of HIV positive people. … It does worry me, because it might happen to me too" (interview 3). Further, while only Buyiswa had fulltime, formal employment, the implications of her HIV status for job security were her primary concern in life, particularly since farm work was physically demanding (for an ill person; interview 1).

In addition to contributing to poverty, being HIV positive can moderate poverty and wellbeing where it provides an opportunity to access social assistance in the form of a disability grant (received by many PLWHA). The reason why both Pumza and Zoleka had 'fewer worries' is that they were receiving disability grants, and in Zoleka's case this was the catalyst for her beginning to work and save money and thus improve her family's situation. While both women normalised HIV by saying that "everyone has it" (Zoleka, interview 3), this was facilitated by their access to treatment and it is uncertain whether

[55] See section 5.3.4.1 for Pumza's comments.

they would have held the same view in the absence of HAART. In fact, Zoleka stated that she would "perceive [HIV] differently" if she were not on HAART since it was the medication that made all the visible markers of disease "disappear" (interview 3). After taking treatment, she had become "the same person I used to be. I'm back to my old clothes, I am not feeling any pain, my feet are no longer swelling, my mouth is no longer reddish. Even if I walk in the street, I'm no longer scared that people are actually staring at me because I have this illness." Access to HAART therefore helped keep HIV on the margins by reducing the visibility of the disease and improving Zoleka's objective and subjective sense of health.

However, the nature of the social security system, and particularly the criteria for the disability grant, was a two-edged sword that threatened the moderating role of HAART for women. As Pumza's earlier comment indicated, while HIV was "forever", the disability grant was not, and the risk of losing the grant[56] was that much greater for women such as Pumza, Zoleka and Lindiwe who are on HAART. Pumza had experienced the precariousness of this situation for women living in poverty while receiving a temporary disability grant for TB:

> Like you don't get a notice when they are taking your grant away. Secondly, when you go to collect your money as you usually do, they just tell you to go renew your grant. You go to the doctor and he'll tell you that you no longer ill. I experienced that. I went to the doctor, I had TB and I only got the money for four months, but he had told me that I qualify for a six month long grant. So when I went to him he said I was well. At that time I did not have anything at home. We lived on left over bread that used to be delivered from shops like Pick 'n Pay. Sometimes it was stale but we had to eat it (interview 3).

For women in extreme poverty such as Pumza, losing a source of income can significantly undermine both economic and psychological wellbeing (Narayan et al., 2000). Conversely, gaining a new or additional source of income can be experienced as having benefits that far outweigh the objective, measurable effects. This was experienced by Zoleka when her daughter began a piecemeal job that paid R20 a week at a time when the family had no

[56] The current social security system in South Africa dictates that PLWHA receiving antiretroviral treatment are likely to lose their disability grant when their health improves sufficiently, with no substantial alternatives for state support and in the context of high rates of unemployment. For more on the debate surrounding this issue and some of its potential unintended consequences, see Simchowitz (2004), Nattrass (2005; 2006b) and LeClerc-Madala (2006). This remained the situation at the time of writing.

other source of income and were living on "handouts". While R20 is a small amount for a family of five by any account, the new source of income contributed to Zoleka's subjective sense of improved wellbeing as well as an objective improvement in her mood[57]. It is therefore not only HIV that can cause disruption or distress (as argued in section 5.3.1). Zoleka made this link in her final interview when she described both financial problems and HIV (independently) as causing worry and weight loss. This was the basis for her position that government should attend to the needs of HIV positive and HIV negative people – a fairly compelling one supported by prominent scholars in the field (Stillwaggon, 2006; Whiteside, 2002).

5.3.5 Concluding comments

The analytical narrative thus arrived at the point that both HIV and poverty had substance in the lives of the five women who told their stories as part of the study. Applying the concept of illness narratives and biographical disruption, there was disruption of some form associated with diagnosis for all of the women, although one woman did not speak about this with a conscious awareness at first. Instead, disruption in her life was untellable and required the idea of an unconscious and unemotional talk to understand more fully her psychological experience. To an extent, women also told the quest/growth narrative. However, it was told in a fairly limited way.

What was clearer was that illness and HIV was not the centre of women's lives unless they were actively ill and not receiving antiretroviral therapy, and even for these women, things would shift with time. If there was to be a constant in the narratives - an underlying narrative or lens through which the stories were told - it was that these were women who knew poverty well, and that this was a context that legitimately edged HIV toward the margin of their lives.

Nonetheless, even where HIV was at the margins, it was constantly intertwined with poverty. In trying to tease apart the relationship between HIV and poverty, women's

[57] This observation was offered by the fieldworker (H.N.) who had met with or seen Zoleka on several occasions at the clinic prior to the formal interview (for the qualitative study). Since H.N. is a social auxiliary worker with experience of serious mental illness, her observation was judged as credible.

narratives sometimes fell on contradiction, revealing both the existence of an interrelationship and the fact that narratives that attempt to reflect life are unfinished, ongoing and confused and contradictory at times (Ezzy, 2000). Women were not always certain themselves, and contradiction and attempts at self-distraction suggest that women sometimes experienced the need to defend against feelings of anxiety and vulnerability. Nonetheless, there were many moments where they were able to articulate their thoughts, opinions and experiences with clarity. Given the opportunity to develop or rehearse a set of rhetorical tools (through the process of creating stories during the research interviews), the women spoke more broadly, deepening the sense of their lives as bigger than a disease, even one that is a "blood disability" that is "forever".

Despite the presence of (unconscious) anxiety, and moments of chaos or disruption or growth or distraction or contextualising, these were women who continued to live their lives and to dream and realise plans for the future. While the difficulties and challenges associated with HIV that were narrated cannot be ignored, it was therefore important to view this in the context of lives that women continued living and that consisted of many things other than a positive HIV diagnosis. Some of the ways in which these findings bear on the results of the statistical analysis presented in Chapter 4, will be discussed in the following chapter.

Taken together, the quantitative results indicated that while the uptake of antiretroviral therapy did not impact on levels of anxiety, *depressive symptoms were significantly lower amongst women who had used treatment for six months than amongst those who had just commenced treatment.* Nonetheless, six-month levels of both depressive and anxiety symptoms remained higher than those of non-infected mothers living in the same community.

It is likely that the lack of change in levels of anxiety amongst HIV-infected women while on HAART was due to relatively low levels even in the absence of treatment (as noted above in 6.1.1.1). Rather than suggesting the failure of HAART to ameliorate women's poor mental health, the stability of anxiety levels therefore further confirms that this may not be a particularly salient clinical syndrome amongst this population of HIV-infected women. However, the possibility that the limited variance of anxiety scores in the present sample contributed to the non-significant finding cannot be excluded.

In contrast, however, both HIV status and access to HAART were associated with depression, suggesting that depression may be a more worthwhile focus for research and services in this population. This is particularly true since women living with HIV continued to exhibit more depression than those who tested HIV negative despite the availability of health-improving treatment. While women themselves did not necessarily make the link consciously, their narratives largely concurred with this result, suggesting that access to HAART was associated with improved physical and emotional wellbeing. This finding manifested both in the characterisation of HIV as a 'common problem' and thus less salient, and reports of other life issues and stressors as more salient. (The issue of relative salience will be discussed further below in section 6.1.5).

Results also showed that changes in perceived and actual health while on HAART were not significant predictors of women's psychological adjustment. In fact they only accounted for a nominal amount of change in levels of depression and anxiety (less than 5%). Thus while women may have experienced substantial benefits to their physical health while on HAART, this did not account for the lower levels of depression reported by those on longer-term treatment. The psychological benefits of HAART access were therefore not simply a function of women believing (subjective) or actually becoming (objective)

physically healthier. Rather most of the improvement in mental health associated with HAART appeared to be explained by non-health related factors.

6.1.4 The impact of HIV status relative to poverty and other predictors

The relative impact of HIV and other sociodemographic, health, mental health and care related factors in predicting women's psychological adjustment was also explored using multivariate analyses (controlling for age and education). All models tested accounted for a substantial amount of variance in the outcome measures although the depression models were substantially stronger than those for anxiety (44-49% explained variance versus 26-32%). This suggests that the most important influences on depression and, to a lesser extent, anxiety were likely to have been identified in the study.

6.1.4.1 Social support, disclosure and psychiatric history

First, several issues of theoretical interest could not be explored in multivariate analyses since they were not significantly associated with either of the outcomes (and were therefore excluded from regression modelling). Most notably, the study was concerned to test the relative impact of different aspects of a multidimensional approach to social support, including the size of women's support networks, different types of support, and support in the context of different relationships (for example, from a partner, friend or mother). Only limited parts of this approach could be tested, with none emerging as significant predictors of either depression or anxiety in HIV-infected women. The only significant finding reported was that lack of satisfaction with overall social support amongst women in general predicted greater depression.

The other main area of interest that emerged from pilot work as well as previous literature was disclosure, including the extent of disclosure, the particular individuals to whom HIV status had been disclosed, the time taken to make one's first disclosure and the time since first disclosure. The role of psychiatric history in determining the psychological sequelae of testing HIV positive could also not be determined since the low positive response rate provided inadequate power for further testing.

While these may be interesting relationships to examine in future research, such fine-grained issues as the relationships within which disclosure occurs and support is received may lack the variance to demonstrate significance in multivariate analyses. (Some further recommendations in this regard are made later in the chapter.) However, qualitative data of women's own accounts did reveal that while all women had disclosed to at least one person, they tended to disclose selectively and deliberately. This both confirmed and extended the finding of the quantitative study that 98.5% of women had intentionally disclosed their status to at least one person. Women attributed non-disclosure to attempts to avoid stigmatising attitudes and behaviour that were anticipated based on careful consideration of the relevant individuals in their households, families or communities. While the avoidance of stigma may have been women's more conscious intent, clearly such strategies had implications for preserving their emotional stability as well.

6.1.4.2 Coping and anxiety

With regard to those predictors that could be tested in regression modelling, *only coping strategies predicted anxiety*. Amongst HIV-infected women, greater use of avoidant coping (denial, self-blame and reducing efforts at coping) and less frequent use of active coping (instrumental and emotional support, positive reframing and planning) predicted greater anxiety. Amongst women in general, including but not limited to those living with HIV, avoidant coping also predicted greater anxiety as did more frequent use of substances such as drugs and alcohol.

Health-related factors (CD4 count, HAART status and perceptions of physical health), social support (availability and satisfaction), living in poverty, having an HIV-infected child and the use of other coping strategies such as humour, religion and self-distraction were *not* associated with increased anxiety. The manner in which women typically dealt with challenges or stressful situations in their lives (their coping strategies) therefore also best explained how women dealt with HIV, including the levels of anxiety they experienced. Along with HIV status, self-reported anxiety was not determined by how ill women were, caring for an HIV-infected child, the quality of their social support system or the extent of the poverty in which they lived.

6.1.4.3 The role of income, health and coping in depression and adjustment in general

Predictors of depression were more varied. Amongst HIV-infected women specifically, the use of avoidant coping (as with anxiety) as well as poorer perceived physical health and irregular household income predicted *higher* levels of depression. Moreover, being HIV positive and having an irregular household income predicted greater depression to an equal extent.

Thus living in a household without a stable, predictable income *was as distressing to women as being HIV-infected.* This is a particularly important finding of this study that will be discussed further below (in section 6.1.5). The use of substances (as with anxiety) and less satisfaction with social support also predicted higher depression amongst women in general, but to a lesser extent than being HIV-infected.

Overall, the use of *avoidant coping was the best predictor of adjustment* in multivariate analyses, with regard to both depression and anxiety. Factors that did not did not contribute independently to depression amongst HIV positive women were: poorer physical health (as objectively assessed by higher CD4 counts and more time spent in hospital), a more recent HIV diagnosis, caring for an HIV-infected child, higher poverty-related deprivation (which included low levels of income and material goods) and a lack of available social support.

One potential explanation for the lack of significant findings with regard to social support is an overlap between social support and coping. While multivariate analyses did not support the significance of any of the social support variables considered, adaptive coping, which included instrumental and emotional support amongst other strategies (based on the factor analysis conducted with the present sample), did emerge as a significant predictor of anxiety. This suggests that social support may in fact play a role in predicting women's adjustment. However, the current data supported its role as part of women's approach to coping more generally rather than as a factor in and of itself.

The relevance of coping in understanding psychosocial wellbeing was also supported by the qualitative data. Women's narratives referred to the use of various denial-like processes, including self-distraction, acceptance and the universalising or reframing of

HIV as something that 'everybody had'. These strategies were often used unconsciously in order to mask underlying anxiety and alleviate distress, an objective that was most feasible when women were not acutely ill and thus confronted with the reality of their disease.

6.1.4.4 The significance of women's perceptions and ecological proximity

Overall, given the findings discussed above, women's perceptions and subjective experiences were more important than objective, measurable characteristics of themselves and their households or environments in determining depression and anxiety. In the case of anxiety, only psychological factors were significant, namely coping. However, even where non-psychological factors were significant, for example, in the case of health which predicted depression, it was the individuals' perception of how ill they were, rather than their objective health status, that was predictive.

Similarly, in the case of poverty, the absolute value of household income was less significant than how stable and regular household income was and therefore whether women experienced their households' financial security as predictable. Even in the case of a psychological predictor such as social support, there was a differentiation between the actual availability of support that did not independently predict depression or anxiety, and women's satisfaction with available support that did predict depression. This finding might also shed light on the fact that very little of the psychological benefits of HAART were explained by improvements in women's physical health. Future research should further examine the role of women's perceptions and other psychologically-oriented/non-health factors in changes associated with HAART.

The fact that household income but not individual income emerged as a significant predictor of women's adjustment is also important. For one, the absence of a stable household income was the only household-level or contextual variable that significantly predicted wellbeing at an individual level. This provides some support for the ecological approach (described in Chapter 2), but suggests that apart from perceptions of health and psychological factors such as coping, only regularity of household income is sufficiently proximal to HIV-infected women's experiences to predict their psychological adjustment.

6.1.4.5 Women's care roles

No aspect of women's care roles considered in this study, either in relation to children or others in the household, made a significant independent contribution to poor mental health. However, there was some indication that atypical aspects of care, in particular, caring for an HIV-infected child or an adult with special care needs due to illness or old age, was associated with greater depression in women. While only a tentative suggestion can be made in this regard, it appears that atypical forms of care as opposed to routine care of children challenged women's psychological adjustment. While the demands of other care roles may have been considerable, the normalisation of women's care of children within the dominant culture may have rendered these roles taken-for-granted thereby diminishing the extent to which they could potentially undermine women's wellbeing.

The term 'burden of care' used in the context of poor women, including those infected with HIV, may therefore be too broadly applied, assuming that all aspects of women's varied care roles are stressors that contribute to the challenges posed by the epidemic. Although perhaps true in part, this research also points to the valued nature of women's childcare work. This was evident in the narratives of those women (captured in the qualitative data) who spoke of a desire to have more children (Nomsa), the prioritisation of their children's needs over their own (Pumza), and even excitement at an increasing number of child dependants despite the obvious financial challenges it presented (Zoleka). All three of these women were living with HIV themselves.

6.1.4.6 A methodological point: Women as primary caregivers

A related methodological issue also arose from the study. The study employed the concept of a primary caregiver as its point of departure for sampling. This was argued to be an important cultural adaptation where most other research on HIV and mental health in mothers only includes women who are biological mothers. This was intended to acknowledge that women other than biological mothers take on important caregiving roles in relation to children in the research setting, and that it is the issue of mothering (rather than being a biological mother) that contributes to women's potential mental health burden.

A further point that arose from the study, however, was that there is not necessarily only one primary caregiver in HIV-infected households in South Africa (and probably in other similar settings in the southern African region). Rather, childcare is often shared amongst several individuals, both youth and adults and households members and other neighbours or extended family (Bray et al., in press). Consequently, care for both children and adults is often a shared undertaking amongst household members and their support networks, particularly where poverty and unemployment results in women (and to a lesser extent men) spending large amounts of time at home and unoccupied (ibid).

Practically, this meant in attempting to recruit women based on the study criteria (see Chapter 3, section 3.2.3.2), women were sometimes included despite adopting an equal rather than primary role in caring for a child under 18 years living in a given household. This may have some bearing on the fact that typical care roles did not emerge as significant predictors of women's psychological adjustment in the study. It was suggested that this did not necessarily mean the absence of an impact, but rather that women's care roles were normalised in the community and that any related burden or distress was difficult to detect. However, in addition to the normalisation of the role, its shared nature may also have moderated its potentially negative impacts on individual women. If care is shared, so too is the potential burden, thereby reducing its relevance or at least potency. Once again, this suggests the need for thoughtful consideration of the concept of women's care burden and the translation of this understanding into sufficiently sophisticated approaches to research.

6.1.5 The relationship between HIV, poverty and mental health

6.1.5.1 The contribution of women's narratives

Multivariate analysis has already been shown to demonstrate that HIV status and the regularity of household income were equally influential in predicting women's levels of depression. This finding was both supported and extended by women's narratives, and is central to the contribution of the present study.

As argued in Chapter 5, while women's own accounts supported the role of HIV in psychological distress, they also pointed to poverty as an underlying narrative through

which women's experiences of living with HIV were continually filtered. HIV was salient at certain moments (for example, when women were diagnosed or ill), but generally for limited periods. However, poverty appeared to be a constant, likened to a "pervasive atmosphere" through which women's lives were lived, both before and after their HIV diagnosis. Further, while women's stories linked emotional wellbeing to living with HIV, they also linked it to living in poverty. Women's narratives were deeply situated and returned repeatedly to the relevance of their social context for understanding their psychosocial wellbeing.

6.1.5.2 The contribution of methodological triangulation

Overall, women's stories contributed to the understanding of the relationship between HIV and mental health by adding depth to the role of context and poverty in particular. The longitudinal approach of the case studies facilitated added depth by pointing to the fact that disruptive periods were time-limited and that while some things changed, poverty remained the same. The fact that women's narratives confirmed an interrelationship between HIV and poverty supported the finding in the quantitative study that while HIV-infected women experienced greater depression and anxiety than non-infected women in their communities, the contribution of HIV and poverty to their mental health was nonetheless equal. In the context of the present study and its particular objectives, the narrative approach and the quantitative one were therefore clearly complimentary. Together the analyses provide an empirically sound and rich understanding of the psychological adjustment of HIV-infected women and mothers living in poor communities.

6.2 COMPARISON OF STUDY FINDINGS WITH PREVIOUS RESEARCH

While a broad review of previous research has been provided in Chapter 2, this section focuses on comparing the main research findings presented above with similar studies. Chapter 2 argued that the literature lacks a consolidated approach as reflected in the range of populations, contexts and methods on which the research draws. Consequently, comparison with many of these studies is either not possible, given the substantive differences in method, or of limited value since differences in findings are likely a function

of sampling differences rather than some more important conceptual issue that makes a theoretical contribution to the field. The studies selected for comparison are therefore those that can contribute to evidence regarding the psychological adjustment of HIV-infected women living in high levels of poverty in South Africa.

6.2.1 The impact of HIV status and disease severity on psychological adjustment

6.2.1.1 Self-reported anxiety

Available research on the impact of HIV status and disease severity on self-reported anxiety in comparable populations is extremely limited. One study that employed a comparable sample of African American women failed to find a difference in self-reported anxiety between infected and non-infected women (Morrison et al., 2002) as did a South African study with both men and women that used a proxy measure (Shisana et al., 2005). Both findings differ from those of the present study. Levels of anxiety in infected women in the present population were also considerably lower than those reported by HIV-infected minority women in the US (Catz et al., 2002) and similar to those of a community sample of US women (Spielberger, 1983a). As suggested previously, this suggests that levels of anxiety amongst both infected and non-infected women in the present study were clinically modest.

With regard to disease severity, Linn et al. (1994) reported no association with anxiety and Comer et al. (2000) that asymptomatic women reported less anxiety than others. Given the inconclusive nature of the present finding, comparison is problematic. However, there is some similarity with findings reported in a study that included two sites in Africa (both found that symptomatic individuals reported higher levels of anxiety than seronegatives, but not those who were asymptomatic) (Maj et al., 1994). Once again, caution is required given that this latter sample comprised mainly men and is therefore substantially different from the present study. Clearly the limited basis for comparison across these findings constrains confidence in its value and prevents any conclusions being drawn.

6.2.1.2 Self-reported depression

While comparable studies are still relatively few, they are sufficient to conclude that the present study corroborated most previous research with regard to the role of HIV status and levels of depression amongst infected women. Most studies also found higher levels of self-reported depression in HIV-infected women than either controls (Johnson et al., 2001; Jones et al., 2001; Jones et al., 2003; Morrison et al., 2002; Tompkins et al., 1999) or community samples (Mast et al., 2004; Reece et al., 2004; Tostes et al., 2004), including amongst women in Uganda and Brazil (both developing countries). Similar results were reported from studies with adults elsewhere in Africa and in South Africa, the majority of whom were women (Jelsma et al., 2005; O'Keefe et al., 1996; Sebit et al., 2003; Shisana et al., 2005).

The present study is the first in South Africa and Africa to confirm this finding in women specifically and that employed both a control group with a confirmed HIV negative status and a standardised tool to assess psychological adjustment (as opposed to proxy measures or an assessment of quality of life). The fact that women already knew their status prior to the study may also be significant. Rochat et al.'s (2006) study of post-partum mothers in South Africa who did not know their status prior to assessment failed to find a significant association between HIV status and depression. This suggests that knowing that one is negative can be psychologically beneficial and that the association found in the present study might in fact be between depression and *known* HIV status rather than HIV status per se.

Several studies failed to demonstrate an association between HIV status and self-reported depression, two of which employed generally comparable studies. However, both Richardson et al. (2001) and Milan et al. (2005) included a much larger percentage of relatively healthy women in their samples than the present study (25-33% with CD4 counts over 500 versus 9%). Richardson concluded that depression was driven by symptoms rather than HIV status, a conclusion less easily tested in a setting such as South Africa where women are more likely to test during the symptomatic stage, hence the under-representation of asymptomatic women in the present sample. The more skewed nature of the present distribution may well account for the difference in finding.

Levels of depression obtained in the present sample were also comparable with results from both local and international research. Overall, 29.2% of HIV-infected women in the present study reported levels of symptoms consistent with probable depression, while levels were higher at 38% for those who did not have access to HAART. These figures fall within the range of figures for studies outside of Africa with comparable samples. Studies from Africa and South Africa also report similar figures for depression, with rates of 27-38% in adults in general (Bganya, 1999; Els et al., 1999; Jelsma et al., 2005; Sebit et al., 2003) and 22 to 35% in women specifically (Mast et al., 2004; Olley, 2006). Figures for pregnant women undergoing HIV testing (Rochat et al., 2006) or post-partum women whose status is unknown in South Africa are also similar (Cooper et al., 1999). Higher figures based on quantitative data have only been reported by Kaharuza et al. (2006) who found that 66% of their Ugandan sample exhibited depressive symptoms. However, this is likely explained by the large number of very ill people in the sample, with 45% of participants having a CD4 count of less than 200.

Comparisons with regard to the role of disease severity are more difficult to make. Only Linn et al. (1994) also failed to find an association between disease severity and depression, while other studies differ both in reported findings and in the particular stratifications employed. For example, one study did not differentiate between symptomatic women and those with AIDS (de Mello et al., 2006), and only one reported comparisons with a seronegative group (Boland, Moore, Solomon et al., 1999b). Even amongst three studies with HIV-infected adults in South Africa, the results were not consistent (Bganya, 1999; Els et al., 1999; O'Keefe et al., 1996). Consequently, the only conclusion that can be drawn is that the present findings remain to be confirmed in future studies.

6.2.2 The impact of somatic symptoms on the assessment of depression

The methodological remedy employed to control for the overlap of symptoms of disease and distress largely confirmed findings from research conducted elsewhere (de Mello et al., 2006; Jones et al., 2001), including that employing the same measure as the present study (the CES-D) (Kaharuza et al., 2006; Milan et al., 2005). This is significant given that this criticism has been held to be particularly relevant in settings and populations such as those

in the present study where somatic complaints constitute the large proportion of (self-reported) symptoms experienced by depressed individuals. Had this finding not held, it might therefore have posed a challenge to the use of simple, self-report scales for the assessment of depression amongst PLWHA in low-resource settings.

It was already noted that one other finding with regard to somatic symptoms in the study was contrary to expectations for black African populations. Other studies in South Africa have reported a predominance of somatic symptoms in depressed black African populations in an HIV clinic (Bganya, 1999) and in primary care practice (Jordaan, Gagiano, & Joubert, 1994). Further, a more recent study in a high HIV prevalence area found evidence of a range of somatic symptoms as manifestations of mental illness (MacGregor, 2003). While not entirely comparable, these studies do raise questions regarding the fact that affective symptoms made a substantial contribution to depression in the present study. Given that other studies have not examined this issue in a population of low income women, this finding will need to be replicated in future research and its implications for the assessment of mental health clarified.

6.2.3 The implications of HAART for psychological adjustment

Previous research with which to compare the study's findings regarding the psychological implications of HAART is negligible. Only one published study reported on women specifically while a handful of others were mostly conducted with bi/homosexual men. The present study's finding that HAART is associated with some improvements in psychological wellbeing, while not rendering mental health concerns irrelevant, is consistent with this literature as a whole. Rabkin et al. (2000) and Mannheimer et al. (2005) in the US, Judd et al. (2000) in Australia, and Jelsma et al. (2005) in South Africa all reported a decrease in depression over a period of between one and two years, although Rabkin noted that the reduction amongst her sample of gay men was clinically modest.

However, two studies that are more comparable in their approach provide inconsistent support. The only study to focus on women reported poorer adjustment to illness amongst women in the HAART era, compared with women in the pre-HAART era (Siegel et al., 2004). While it is unclear how to account for this difference in findings, Siegel suggests

that her own unexpected findings may be a function of women's expectations being raised regarding the benefits of HAART. The reality may have been somewhat different, leaving them feeling demoralised and less well adjusted than they would have been had their initial expectations been lower. This may be in contrast to the present setting where women's initial expectations regarding HAART were probably lower than women in the US sample, given the mixed messages within South Africa's public sector health services regarding the advisability of HAART relative to other alternative treatments (such as nutrition) (Nattrass, 2006a; South African Press Association, 2004). The fact that Siegel et al.'s (2004) sample of women were more educated (40% had more than a high school qualification) and had access to a wider array of social services and treatment facilities for HIV-infected adults than those in the present study may also have played a role.

Nonetheless, Jelsma and colleagues' (2005) research in South Africa conducted with a sample of 70% women provides an important point of comparison. The research confirms two other findings of the present study: First, that an improvement in depression is evident in HAART patients by six months (Jelsma et al. followed patients up for one year) and second, that despite improvement, people on HAART still reported poorer mental health than community members. While the present findings are consistent with Jelsma's on these two issues, it is important to note that the latter study employed a comparison group for which the HIV status was untested and therefore may have included men and women living with HIV. This is in contrast with the present study in which the seronegative status of the comparison group was confirmed. Further, measurement tools in the present study were more appropriate to the question of psychological adjustment, in contrast with Jelsma's research that focused on health-related quality of life and thus comprised a one-item scale on the presence of anxiety or depression rated on a 3-point scale. The present study therefore provides more substantive evidence in support of the impact of HAART.

6.2.4 The impact of HIV status relative to poverty and other predictors

6.2.4.1 The role of income, health and coping

The most substantial findings regarding predictors of depression and anxiety pointed to the role of poverty, perceived health and coping, and are largely substantiated by the available

research. In fact these are three of the more consolidated research areas amongst the pathways to psychological adjustment explored in the literature on HIV-infected women and mothers.

With regard to coping, several quantitative studies from the US (Catz et al., 2002; Commerford et al., 1994; Sherbourne et al., 2003; Simoni & Cooperman, 2000a; Simoni et al., 2000d) and three qualitative studies from Africa have confirmed the salience of avoidant coping as a predictor of psychological adjustment (Austin, 2003; Keogh et al., 1994; Van Woudenberg, 1998). One of the quantitative studies employed a multivariate analysis as in the present study, as well as a large sample (n=847) (Sherbourne et al., 2003). However, they did not include a control group. Nonetheless, this provides one of the most scientifically rigorous points of comparison for the present result.

Catz et al. (2002) and Simoni et al. (2000a; 2000d) also confirmed that greater use of avoidant coping predicted higher depression, while Commerford et al. (1994) reported an association between greater anxiety and emotion-focused coping which included strategies consistent with avoidant coping (namely, self-blame and denial). Catz et al.'s (2002) finding that greater active coping predicted less anxiety was also consistent with the present study, however they failed to confirm the association between anxiety and avoidant coping.

Some differences were also evident with Olley's (2006) findings and are worth noting given that this was the only other quantitative study in Africa to investigate the relationship between women's coping strategies and their psychological adjustment. In a paper reporting on combined data for both men and women, Olley et al. (2004b) reported that coping strategies were not significant predictors of clinical depression in multivariate analyses. Again several difficulties are evident with regard to comparisons: First, Olley used clinical rather than self-reported depression as an outcome; second, although using the same coping inventory as the present study (the Brief COPE), a different factor structure was generated and employed in analyses (Olley et al., 2004b); and third, a still different approach to the use of the Brief COPE was reported for the analysis with women only (Olley, 2006). It is therefore difficult to comment on the apparent differences in findings.

With regard to findings on health as a predictor, the similarity between Olley's (2006; 2004a) findings and those of the present study are more easily suggested. Both demonstrated that CD4 count was not a significant predictor, while more subjective accounts of health were. In the present study this was assessed as perceived physical health, while Olley reported on disability and social impairment. This supports the finding that subjective health rather than objective disease parameters are the best predictors of depression in infected populations (Boland et al., 1999b; Breitbart et al., 1996; Jones et al., 2001; Miles et al., 1997).

With regard to the role of income, several studies reported an association between low individual income and greater depression and anxiety, although multivariate analyses were split between one that confirmed (Simoni et al., 2000d) and two that did not confirm the impact on depression (Richardson et al., 2001; Van Servellen et al., 1998). However, only one study reported on the impact of family income, a variable that more closely approximates the present study's report on the regularity of household income (Bennetts et al., 1999). It is likely that what Bennetts et al. intended as family income in Thailand is the same as household income in the South African context where household composition can vary and departs from a nuclear family model. Bennetts et al. reported that family income did not independently predict depression in recent HIV-infected mothers.

In a more similar context to the present study than Bennetts et al. (1999), and with a more similar population, Kaharuza et al. (2006) reported recently that having no income predicted depression amongst Ugandan adults undergoing antiretroviral screening. No reviewed studies reported a comparison between women's HIV status and income/poverty-related factors as predictors of depression or anxiety (in multivariate analyses). Taken together the comparative findings strongly suggest a role for income of some kind, but do not provide a precise comparison for the present study.

6.2.4.2 Social support, disclosure and psychiatric history

Social support, disclosure and psychiatric history were all variables of interest in the present study that could not be adequately tested in multivariate analyses. Limited comparative data is available for HIV-infected women regarding the role of psychiatric

history and that which is available differs in the conclusions drawn (Gielen et al., 2005; Mellins et al., 1997; Pergami et al., 1993; Sherr et al., 1997; Van Servellen et al., 1998). However, from a clinical perspective, this still appears to be a worthwhile avenue for future research, given that previous trauma or psychiatric history is generally understood to be a particularly good predictor of future mental health problems. In addition, research with HIV-infected adults in general (as opposed to women only) has demonstrated that past psychiatric history is a particularly strong predictor, partly since pre-existing mental health problems (including substance use) are present in many groups most affected by HIV (Kalichman, 1995; Lyketsos et al., 1994; Lyketsos et al., 1996; Perry et al., 1993).

With regard to disclosure, no other quantitative studies examined aspects of disclosure as a predictor of psychological adjustment in women. However, previous research concurred with the present finding that most women had disclosed their HIV status to at least one person (Comer et al., 2000; Sherr et al., 1997; Simoni et al., 2000a; Tompkins et al., 1999). The fact that many women disclosed to a small number of people suggests the importance of differentiating between disclosure per se (to at least one person) and the extent of disclosure.

With regard to social support, previous findings are very mixed although there is evidence that differs from the present finding that social support was not an independent predictor of adjustment (see, for example, Bganya, 1999; Van Servellen et al., 1998). Linn et al.'s (1994) finding that support did not have a main effect on depression in infected women may be instructive. This finding is similar to those of the present study in two respects: because the present study found an association for both depression and anxiety, but a main effect for neither; and because social support and coping could overlap, as indicated earlier (in section 6.1.4.1). This suggests that while social support may play a role in women's adjustment, it is likely to be a more complex one than a simple linear relationship.

6.1.4.3 Women's care roles

Out of several possible care-related associations tested, the present study found only a marginal association between greater depression and caring for an HIV-infected child and providing special care to adults. This is contrary to other studies that have reported

associations with women's childcare role. For example, Van Servellen (2002) reported that a greater number of dependants was associated with higher levels of depression and anxiety, and Milan et al. (2005) that maternal role difficulty was associated with greater depression.

However, previous findings regarding having an HIV-infected child (Bennetts et al., 1999; Mellins et al., 1997; Simoni et al., 2000c) and having a child in general (Reece et al., 2004; Sherr et al., 1997; Te Vaarwerk et al., 2001; Tompkins et al., 1999) are mixed, and no studies with HIV-infected women reported the implications of caring for an adult (not necessarily due to his/her HIV-related illness). The systematic examination of HIV-infected women's care roles as a predictor of their psychological adjustment is therefore in its relative infancy in terms of establishing a consistent evidence base.

That said there is considerable evidence to support the suggestion that women's childcare roles in particular may have been normalised in the present study as well as the fact that the role was valued and even prioritised by women themselves (Ciambrone, 2003; De Marco et al., 1998; Hackl et al., 1997; Mayers et al., 2005; Sandelowski et al., 2003; Van Loon, 2000). Two qualitative studies conducted in South Africa have explored some of the complexities of women's care roles, including the extent to which care is burdensome (Long, 2006; Muller & Pienaar, 2004). However, the present study was the first in Africa or South Africa to explore some of these issues in a quantitative study with HIV-infected women.

6.2.5 Women's stories of HIV, poverty and mental health

Chapter 5 has already suggested several ways in which the present findings regarding the role of poverty speak to certain bodies of literature, not all of which are specific to the field of HIV. For example, women linked their socioeconomic status to emotional wellbeing in the same manner as many other people living in poverty across the developing world who were interviewed as part of a large-scale World Bank study (Narayan et al., 2000). Women's narratives also pointed to the interrelationship between poverty and HIV/AIDS, an argument put forward by prominent economists and sociologists in particular in recent times (Stillwaggon, 2006; Whiteside, 2002).

The fact that women were not "narrative wrecks", particularly beyond the time of diagnosis, and did not all consider HIV the most significant stressor in their lives, also concurred with the findings of several previous studies. In particular, Ciambrone (2003) reported that women in her US sample that considered HIV as the most stressful event in their lives tended to come from better backgrounds. This suggests that women who had experienced greater hardship in their lives, including living in long-term poverty such as women in the present study, were more likely to experience HIV as one of a range of stressors and therefore not completely novel and overwhelming (Bungener et al., 2000; Semple et al., 1993; Weinberg et al., 2004). This was further confirmed by Kalichman and Simbayi's (2003b) study in Cape Town, South Africa, in which residents identified HIV as part of a cluster of stressors related to their social context – less serious than crime but not different from violence and unemployment. Poverty was the either the most frequently mentioned problem or one of them in several other studies as well, conducted either in the US (Gillman et al., 1996; Marcenko et al., 1999; Semple et al., 1993; Smith et al., 2001) or in Africa (Keogh et al., 1994; Olley, 2006; Van Woudenberg, 1998). Like in the present study, mothering was arguably the next most frequent set of issues for HIV-infected women (Bungener et al., 2000; Bunting, 2001; Ciambrone, 2003; Mellers et al., 1994; Sandelowski et al., 2003; Wesley, 2003).

What is perhaps important to note is that while the present study confirms many of the previous findings, its particular contribution was to present them in an integrated manner in a setting where there was a distinct lack of research on the mental health of HIV-infected women living in poverty. The exercise of comparing and contrasting the present set of findings with those of previous research is clearly an important one. However, it should be emphasised that this remains new data for the South African and African context that must be confirmed with further research.

6.3 STUDY LIMITATIONS AND PARAMETERS

6.3.1 Limitations of the quantitative study

The quantitative study has several potential limitations, in addition to those points raised in section 6.1. First, due to its cross-sectional nature, no conclusions regarding causality can be drawn. Instead, key variables that impact on adjustment have been identified and can be further explored in future longitudinal studies that permit the exploration of causality.

Second, the standardised scales that were employed had not been normed, standardised and clinically validated for the study population. However, no such scales developed in South Africa were available and all scales had been standardised with other populations and administered successfully with PLWHA. Further, both the depression and coping inventories selected had been used previously with HIV-infected women in South Africa. All scales also demonstrated good reliability in the present sample and were simple and easy to administer. This was important given the nature of the study population (low levels of education).

Third, while self-report measures can overestimate levels of depression and anxiety, and no clinically validated norms were available locally, the measures were intended for the purpose of screening and group comparisons rather than diagnosis and the reporting of prevalence. The instruments were therefore appropriate given the study objectives. In addition, the inclusion of a control group facilitated the generation of comparable scores for the study population.

Fourth, while the use of self-report measures of depression in HIV-infected populations has been criticised, the impact of somatic items was empirically investigated and determined not to influence the study findings.

Fifth, randomised sampling could not be employed and thus conclusions regarding the representivity of the sample and the generalisability of findings to HIV-infected women and mothers in the chosen community should be carefully considered. However,

roll-out in their community. The present study was concerned only with women whose HIV status had been confirmed, whether they tested negative or positive, and women who were not yet receiving HAART for clinical reasons (i.e. CD4 count over 200).

Sixth, randomised sampling could not be employed and thus conclusions regarding the representivity of the sample and the generalisability of findings to HIV-infected women and mothers in the chosen community should be carefully considered. However, comparison of sociodemographic study data for both the women and their households with the most recent available census data[58] for Crossroads (the community in which most of the participants lived) revealed a high degree of concordance (see Table 6.1 below) (City of Cape Town, 2006). This suggests that representivity of the community sampled was good, particularly given the reliance on consecutive sampling. Key variables on which a difference was noted can be explained by differences in the proportion of PLWHA in each sample. For example, income was lower in the study sample which purposively sampled HIV-infected women (72%) than in the community-wide sample in which HIV prevalence is nearer 25%. This was predictable given the association between HIV status and income demonstrated in South Africa (Booysen, 2003).

Table 6.1 Comparison of study data and Census 2001 data for Crossroads

Variable		Females/HH (%):	
		Study sample 2005/6	Crossroads Census data 2001
Language	Xhosa-speaking	98	96
Education	None	3	11
	Grade 8-11	62	42
	Grade 12	12	17
Employment	Paid employment	29	41
Income	Monthly individual income (R0-R1 600)	99	88
	Annual household income (R0-R19 200)	68	78
Amenities	Inside tap	48	46
	Inside toilet	58	41

With regard to the broader generalisability of data, the study findings cannot be generalised to all PLWHA or all HIV-infected women in South Africa. Instead, the sample was chosen

[58] Other more recent data sets that capture sociodemographic information for South Africa are not disaggregated at the ward level required for this comparison.

CHAPTER 7. CONCLUSIONS AND RECOMMENDATIONS

In this final brief chapter, concluding comments will be presented and recommendations made on the basis of the findings and their potential contribution to the field of HIV and mental health in the southern African region. Both recommendations for future research and policy and service provision will be put forward.

7.1 CONCLUDING COMMENTS

The question posed at the outset of this dissertation with regard to South African women was: Does HIV matter when you are poor and how?

There is considerable evidence that indicates that HIV positive women and mothers who live in poverty are a group at high risk for mental health problems. Still further evidence examines this risk empirically. However, this dissertation has demonstrated that the majority of empirical research has been conducted in countries where the *minority* of poor, HIV-infected women live. Futher, these women differ substantially from the research populations included in most studies (for example, MSM and IVDU). Given the many difficulties in transferring knowledge, and the substantial number of women in the most affected region, namely sub-Saharan Africa, this is a significant shortcoming.

"Scarce resources" is an argument that has typically been put forward for *not* addressing the mental health needs of men and women in this region. However, I argue that mental health needs are substantial and that the allocation of scarce resources must therefore be driven by thoughtful, evidence-based policy. Much of the dissertation has attempted to convey and remain mindful of the complexities of answering the broad research question. However, it is equally important to distil the key contribution of the research in a manner that is more easily translated into policy and praxis.

The question posed at the outset had two parts: first, does HIV matter, and second, how? Based on the research evidence gathered, the answer to the first question is yes. HIV-infected women living in poverty do exhibit higher levels of psychological distress than other non-infected women living in their communities. Levels of both anxiety and depression amongst infected women were elevated relative to controls for that population. However, levels of anxiety were relatively low in both groups compared with clinical norms for other populations. This was in contrast with levels of depression that were substantial, with just less than one in three HIV-infected women reporting levels of depressive symptoms consistent with probable depression.

Importantly, while longer-term use of antiretroviral therapy was associated with reduced depression (but not anxiety), HIV-infected women were still more likely to be depressed than non-infected women. At least with regard to depression, the research therefore supports the conclusion that poverty did not create a ceiling beyond which the psychological impact of living with HIV could not be detected. HIV positive women experienced a greater mental health burden than HIV negative women living in the same community despite the existent poverty related stressors to which both groups of women were already exposed.

The second part of the question, *how* does HIV matter, was answered in several ways by the research. First, it was clear that the psychological benefits of HAART for HIV-infected women were not as a result of improvements in their health, whether actual or perceived. This in no way suggests that the health benefits of HAART were insubstantial, only that non-health related factors contributed substantially to the extent of mental health problems experienced by these women. Issues other than health are therefore needed to explain any mental health benefits that women experienced, in some cases, in parallel with health benefits.

Having said that, perceived health was one of four significant variables that explained the extent of depression in HIV-infected women in general, the other three being the use of avoidant coping, irregular household income and HIV status. With regard to HIV status, this meant that even if women were similar in all other respects, that fact that they had been diagnosed HIV positive contributed to them being more depressed. The same was not

true of anxiety. While HIV-infected women experienced greater levels of anxiety than non-infected women, this was not explained by their HIV status and, as already noted, all women's anxiety remained sub-clinical.

Common to both anxiety and depression, however, was that they were best predicted by women's coping strategies. Thus amongst women who were HIV-infected, those who dealt with the situation through avoidance were most likely to be depressed and most likely to be anxious. The manner in which women typically dealt with challenges or stressful situations in their lives (their coping strategies) therefore also best explained how women dealt with HIV. Although HIV status, health and income also contributed to the understanding of depression in infected women, their contributions were relatively equal and were less significant than that of women's coping strategies. Of importance, this meant that testing HIV positive and having an irregular household income contributed equally to the extent of women's depression. Put differently, living in a household without a stable, predictable income was as distressing to women as being HIV-infected.

Importantly, women's own accounts of their lives as someone with a positive diagnosis further reinforced this point. HIV was important to women at certain points in their lives, particularly when they were diagnosed or ill, and was linked to their social and emotional wellbeing. However, while the impact of HIV tended to be time-limited, particularly where women had access to antiretroviral therapy, the fact that women lived in poverty was a pervasive influence in their lives. Women's experiences of living with HIV and life in general were therefore continually filtered through the realities of being poor. Being HIV positive was about being poor *and* HIV positive for these women. Women's narratives returned repeatedly to the relevance of social context for understanding their psychosocial wellbeing. The importance of acknowledging that HIV-infected women lived in poverty was therefore powerfully communicated.

7.2 RECOMMENDATIONS

7.2.1 Recommendations for further research

The following research recommendations are made with a view to addressing some of the limitations of the present study noted in section 6.3, as well as further extending the contribution of the study to the field. Those points that have already been made in the discussion will only be briefly revisited here, while others will be discussed in more detail.

First, a broad point that needs to be made is that the current study reports on new data for a black African population in South Africa. The majority of studies from outside of Africa were conducted with different populations (for example, MSM and IVDU) and only two studies within Africa focused exclusively on the mental health or quality of life of poor, HIV-infected women. Given the limited available data in the region within which to situate these findings, further research must be conducted with women in order to confirm and extend these findings. This is an important part of building a more consolidated body of literature needed to drive evidence-based policy. However, in attempting to further this objective, research that is conducted must also be methodologically sound and employ variables that can be readily targeted in interventions to reduce women's mental health problems (for example, coping strategies) (Collins et al., 2006).

Second, given the importance of depression amongst women living with HIV/AIDS and the goal to inform policy, further research in this area is needed. One first step would be to conduct a clinical validation study in order to determine clinically appropriate cut-off scores or ranges with which to identify women who are either at-risk for depression, or currently depressed. This would serve as a basis to identify those in need of referral for intervention. While some African researchers have preferred the use of clinical diagnostic instruments such as the MINI (Olley, 2006) and CIDI (Maj et al., 1994) to screening instruments such as the CES-D, the use of brief, easy to administer tools that do not require training facilitate an easier translation into service provision. Clinical validation is, however, a necessary adjunct prior to their use in a service environment.

Third, relatively little research has been conducted on anxiety in HIV-infected women and the low levels in the present study may have constrained the emergence of a sophisticated model of anxiety in HIV-infected women. Future research is therefore needed to clarify the role of anxiety in living with HIV as well as evaluating the replicability of the present findings.

Fourth, longitudinal research is required in order to investigate causal relationships between the important variables identified in the current research. (As noted in Chapter 3, practical constraints on recruitment prevented a longitudinal approach to the present quantitative study.) This could also serve to extend the current research that only included women who had been on antiretroviral therapy for up to six months. As treatment programmes become more established in South Africa and the region, the mental health implications and needs of women on longer-term treatment will become a topic of greater importance.

Fifth, on a related matter, the research suggested that non-health related factors accounted for changes in psychological adjustment reported by women on HAART, but did not investigate the specific pathways to change. Future research could clarify these pathways as well as investigating other aspects of the relationship between HAART and psychological adjustment that were beyond the scope of the present study (for, example, the predictors of adherence to treatment).

Sixth, several points that emerged in the current research require further investigation since methodological constraints prevented their more detailed analysis. These include: research that incorporates larger numbers of asymptomatic women in order to clarify the impact of disease severity on women's psychological adjustment; research into the role of psychiatric history as a predictor of women's current and future adjustment; and research into the relationship between disclosure and women's adjustment. Research could also serve to clarify women's experience of their childcare and other care roles, including the extent to which the notion of burden of care has relevance for women. Further, predictors of women's adjustment related to their care roles must be re-conceptualised and evaluated in further research.

Seventh, the current findings suggest the value of a qualitative research approach in driving policy and service provision, particularly when conducted in conjunction with rigorous, quantitative research. While the quantitative component of the present study mapped the issues in a systematic and generalisable manner that a qualitative study could not, the addition of the qualitative lens facilitated a richer and more in-depth understanding of women's experiences of living with HIV. This can serve as an important conceptual framework from which to plan and undertake future interventions with this population. While triangulated research may not be necessary, qualitative studies best serve policymaking when designed in such a way that they build on previous quantitative research findings or contribute to the development of future ones.

Eighth, resilience and the promotion of resilience in HIV-infected women is an important avenue for future research. While beyond the scope of the present study, the qualitative study suggested that some women continue to function relatively well despite their adverse circumstances. Research into resilience would compliment the current research that tends to inform a risk approach to intervention. The most successful interventions are likely to be those that both reduce attitudes, behaviours or environmental characteristics that promote risk, while simultaneously fostering those that build resilience in women.

Finally, while this research has attempted to address a specific gap with regard to research on women, future research with men living in the same settings is also necessary. One useful avenue for such research would be the supportive and protective roles that men can play in the lives of women living with HIV. As yet little research has focused on the positive roles that men can play in the context of HIV/AIDS. (For recent examples, see Bray et al. (in press), Denis and Ntsimane (2005), and Montgomery, Hosegood, Busza and Timaeus (2006).)

7.2.2 Policy and service implications for women living in poor, high HIV prevalence areas in South Africa

It was not the objective of the present study to develop policy. However, the study aimed to generate an evidence-base with which to *inform* policies and services for women living

in poor, high HIV prevalence areas in South Africa. Accordingly, the key implications of the study for policy can be noted.

The clearest recommendation that emerges from this evidence base is that HIV-infected women require mental health services and to a greater extent than other women living in poor communities. Given that research already indicates that the burden of disease associated with depression is high amongst women in South Africa (Moultrie & Kleintjes, 2006), the present research indicates that HIV exacerbates this burden. It is recommended that referral to mental health services should be incorporated into the routine practice of public sector HIV clinics in order to address the substantive psychological needs of HIV-infected women.

This is not to suggest that all women in poor communities should not have access to mental health services, but rather that the allocation to clinics or communities in which a larger proportion of women are living with HIV should be greater than to those less affected. Further, the need for such services is not negated by the role-out of HAART although services may need to address themselves to different issues as women remain on treatment for longer. Such an approach would require the reversal of mental health's Cinderella status within public sector health services in countries such as South Africa (Miranda et al., 2005). An approach that integrates the psychological and social needs of HIV-infected women with current medical approaches would be consistent with the recent recommendations of the World Health Organisation (2005b; see also Baingana et al., 2005; Freeman, Patel, Collins, & Bertolote, 2005). More importantly, it would also build on the South African government's policy to provide comprehensive, community-based mental health services that articulate with other health services (Department of Health, 1997).

Given the recommendation for routine referral to mental health services, this research provides a preliminary evidence base with which to develop tools to enable staff at public sector clinics to make such referrals. Given the scale of the epidemic in these communities, and the resource constraints currently experienced in South Africa's public sector health services, an approach that requires a high-level of skill and expertise is unlikely to be feasible and sustainable. The human resource implications of such a service are beyond the scope of this dissertation. However, it has been an important consideration to conduct this

investigation with instruments such as the CES-D and Spielberger State Anxiety Inventory that could more easily be taken up in South Africa's service environment.

In addition to the use of these simple tools for routine screening for referral, the research also identified other characteristics of at-risk women that could be employed at service level to assist with the targeting of services. In the present population it was HIV-infected women who employed avoidant coping, those who lived in households with an irregular income and those who perceived their health as poor that were most likely to present with mental health problems. Amongst women in general, lower satisfaction with one's social support and the use of drugs or alcohol were additional predictors that could contribute to a list of risk factors in settings where women's HIV status is not known. The combination of two such tools – easily administered mental health inventories and a set of risk factors – could assist policymakers in finding a balance between addressing women's rights for accessible mental health services (as noted above), while providing them with a realistic and effective strategy for identifying women in need of such services. This would allow services to be rationalised, given the large demand on services and the limited availability of skilled staff to which referrals could be made.

Finally, two related recommendations can be made with regard to the nature of referrals. One approach that is certainly most feasible in the short-term is to ensure that all public sector HIV clinics have comprehensive and up-to-date directories of psychosocial services available in and near their area at their disposal. This research team found that this was often a gap, even where such resources were available in the community. Clearly, this means that the compilation of such listings is no more important than awareness raising and dissemination of resource directories amongst frontline service providers most likely to make such referrals.

A second approach with a longer-term view is to further investigate two avenues for targeted interventions with HIV-infected women in poor communities: namely coping strategies and stable income. While strategies for addressing the regularity of income are beyond the scope of this dissertation, the research has provided compelling evidence regarding the importance of income as a social problem to which comprehensive HIV-related services should be addressed. This is particularly so given the salience of poverty in

women's own accounts. In the absence of attention to this issue, interventions that target issues that are otherwise theoretically appropriate (for example, coping), may nonetheless be undermined by their failure to meet the needs and experiences of women themselves.

With regard to coping, the fact that avoidant coping emerged as the best predictor of psychological adjustment indicates that it is an appropriate and promising focus for future mental health interventions with this population group. Further work will need to be done to develop the substantive content of such an intervention. However, the fact that coping was a strong predictor of mental health outcomes in both HIV-infected women and women in general, suggests that the development of such content would have broad applicability to women in poor communities in South Africa.

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Appendix A. Letter of approval from Department of Health

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REQUEST TO CONDUCT RESEARCH AT A PRIMARY HEALTH CARE FACILITY, PGWC: "I'M HIV+, I'M POOR AND I CARE FOR YOUNG CHILDREN": AN INVESTIGATION OF THE PSYCHOLOGICAL WELL-BEING AND COPING OF LOW SOCIO-ECONOMIC STATUS MOTHERS AND WOMEN CAREGIVERS IN THE ERA OF HAART

The Directorate: HIV/AIDS/STI & TB hereby grants you permission to proceed with the research study, as described in your research proposal. I recommend that you discuss the selection of an appropriate site with Ms B Smuts and Dr N Slingers. We welcome the kind of research that you propose and hope that it can impact on our programme meaningfully in the future.

We would like to remind you that we are not liable for any damages/harm incurred upon your person or property or that of any of your research team. We would also like to re-iterate the need to maintain patient confidentiality and trust that all the members of your research team will maintain this.

Yours sincerely

Dr K. Cloete
DIRECTOR: HIV/AIDS/TB/STI
Date: 23 May 2005

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Appendix B. Study information sheet for clinic staff and local service providers

RESEARCH TO BE CONDUCTED IN CROSSROADS AREA

INFORMATION FOR CLINICAL TEAM

Study title: **An investigation of the psychological well-being and coping of low socio-economic status mothers and women caregivers in the era of HAART**

Investigator: Mrs René Brandt

Affiliations: Doctoral student, Aids and Society Research Unit and Department of Psychology, University of Cape Town
Research associate, Human Sciences Research Council

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Project fieldworker and recruitment manager: Hilda Ntjana
Cell: 083 617 4253

DETAILS OF STUDY:

The study aims to explore the associations between the mental health of mothers, and their HIV and treatment status. The challenges to women's caregiving and psychological well-being will be examined within the context of their multiple roles of living with HIV, mothering and dealing with the general stressors associated with poverty. Further, the implications of these multiple roles for women's adherence to antiretroviral therapy will be examined.

The data collection for the project will be conducted between June and December 2005. The study will recruit a total of 200 women living in and near Crossroads who have at least one child still living in their household for whom they are either the mother or the primary caregiver. Of these 200 women:

- 50 must have tested HIV negative
- 50 will be HIV positive, but not on HAART
- 50 will have been on HAART for less than two weeks
- 50 will have been on HAART for between 6 and 7 months

Women who are actively involved in providing psychosocial services to PLWHA will not be eligible to participate in the study, as they are not considered to be sufficiently representative of the majority of women living with HIV in the Western Cape and South Africa.

The women's participation, including those attending the ARV clinic, will involve the following:

- **Once-off interview during which a structured questionnaire will be administered (duration: 2 hours).**
  The questionnaire will cover socio-demographic and household information, caregiving history, and HIV and other health-related information. It also includes four brief standardised measures which assess depression, anxiety, social support and coping strategies.
- **Giving permission for project staff to collect medical data from the participants' clinic files (viz. CD4 count, viral load, treatment regimen, adherence information).**
- A sample of not more than ten of the HIV positive women will also be selected and asked to participate in three further **in-depth interviews** over a six-month period.

PRACTICAL IMPLICATIONS OF RESEARCH FOR CLINIC STAFF:

- The clinic staff will not be required to be directly involved in the research process. The project is self-staffed and self-funded. However, in consultation with members of the clinical team, a method of recruitment would be set up. One option which seems especially feasible in this regard is to use the treatment readiness sessions which are compulsory for all patients on ARVs as a forum to request participation. This would involve some assistance from counsellors, and no input from other members of the clinical team. With the participants' permission, we will also be requesting access to their medical files, but the data from these files will be collected by the fieldworkers themselves.
- If a suitable arrangement can be made, we would like access to a room on an adhoc basis in order to conduct the interviews with women privately. The times of day and days of the week when this work will be conducted would be negotiated with clinic staff.

PRACTICAL BENEFITS OF RESEARCH FOR CLINIC STAFF AND COMMUNITY:

- As a research team, we will provide feedback at the completion of the project on issues which can assist clinic staff in patient management.
- Key planned project outputs which may be useful to service providers are:
  - A **list of factors that place HIV positive women at risk for poor mental health and poor adherence to treatment.**
  - Some **brief tools for counsellors** in particular to use to identify these risk factors.

    These two outputs aim to enable service providers to more easily identify patients at-risk so that services can be rationalised, given large demands on services and the limited availability of skilled staff.
  - A **directory of psychosocial services** available in and near the Crossroads area.

    The rationale behind this output is to facilitate networking within communities and to educate service providers and clinic staff as to available services in and near Crossroads to which at-risk patients in need of intervention can be referred.
- More broadly, the research also aims to make recommendations about the kinds of psychosocial services which can enhance women patients' quality of life and psychological well-being, as well as enhancing their adherence to treatment.
- On a more informal basis, given the clinical training of the project investigator, we could also provide input or support to the patient advocates and adherence counsellors where this is requested.

REDUCING POTENTIAL PROJECT BURDEN ON PARTICIPANTS AND STAFF:

- My primary fieldworker, Hilda Ntjana, and I are clinically trained (and registered with the Social Work and Health Professions Councils respectively) and will offer individual sessions to patients if we feel our questions provoke issues for them or result in them feeling uncontained. This will potentially add value to the clinical service, and aims to minimise any potential burden created by the research process for either the patients or the clinical staff.

PERMISSION TO CONDUCT THIS STUDY HAS BEEN GRANTED BY THE HIV/AIDS DIRECTORATE OF THE PGWC. ETHICAL APPROVAL HAS ALSO BEEN GRANTED BY THE UNIVERSITY OF CAPE TOWN

Appendix C. Consent form – English

UNIVERSITY OF CAPE TOWN

Department of Psychology

CONSENT FORM

Study on women's well-being and caregiving

If you sign here it means that you will let us interview you. It means that you understand what the study is about and what we want you to do. It also means that you understand that we will keep everything that you share with us confidential, and that you can say so at any time if you don't want to answer one of our questions or take part in the study anymore.

1. Caregiver:

   Name (print): _____ Signature: _____

   Date: _____ Place: _____

2. Witness/interviewer:

   Name (print): _____ Signature: _____

   Date: _____ Place: _____

Thank you for agreeing to be part of this study.

----oooOooo----

Respondent no:

Appendix D. Consent form – Xhosa

UNIVERSITY OF CAPE TOWN

Department of Psychology

IFOMU YESIVUMELWANO

Uphando ngobunjani kwabafazi kunye nokonga

Ukuba uyatyikitya apha, lo nto ithetha ukuba uyasizumela ukuba sikubuze. Ithetha ukuba uyayazi ukuba uphando lungantoni kwakunye nento esifuna uyenze. Iphinda ithethe ukuba unolwazi lokuba yonke into othe wayithetha nathi iyakuba semfihlakalweni, nokuba ungatsho nangeliphi na ixesha ukuba awufuni kuphendula omnye wemibuzo okanye ukuthabatha inkxaxheba kolu phando.

1. Umongi:

   Igama (xabela): _____ Utyikityo: _____

   Umhla: _____ Indawo: _____

2. Ingqina/umbuzi:

   Igama (xabela): _____ Utyikityo: _____

   Umhla: _____ Indawo: _____

Enkosi ngokuvuma ukuthabatha inkxaxheba koluphando.

----oooOooo----

Respondent no:

Appendix E. Information sheet – English

UNIVERSITY OF CAPE TOWN

Department of Psychology

INFORMATION SHEET

Hello, I am René Brandt. I am a clinical psychologist and a student at the University of Cape Town. I am conducting a study on how women living in your community affected or infected with HIV deal with stresses in their life and manage their household duties and children. I hope that through speaking to women, I can better understand their experiences, and can advise community leaders how to provide women like you with the kind of psychological services which will help to improve your quality of life.

So what will you have to do if you decide to participate in my study?

One of two women who work with me will meet with you to ask you questions about how many people live in your house and who looks after your children. We will also ask how you have been feeling recently, how you are coping with things in your life, and the kinds of support that you get from other people. The interview will last about two hours and you will be allowed to speak in the language of your choice. We also want to look at your medical file to find out how well you are and whether you are taking your medication. We will ask your doctor to show us your results on tests called a CD4 count and a viral load.

We might also ask you to talk to us a few more times about some of the same things, just in more detail. We would like to tape record these later meetings so that we can listen to and think about what you have said again afterwards.

Will we keep everything you tell us private?

Yes. All the information which we collect, including the audio cassette tapes, will be stored in a locked cabinet at our office and only members of the research team will have access to it. All the members of the team will keep the information private and confidential, and will not give your name or any of your personal information to anyone else. This is something that we take VERY seriously. When we have collected the information from you and the other women we are speaking to, we will put it together so that no-one can find out what you told us.

What will happen to you if you don't want to answer our questions or be part of the study anymore?

Nothing. Saying you don't want to answer a question or do something WON'T make something bad happen to you. You can still come to the Clinic and you will get the best treatment that the doctors can give you just like they always have.

What can you do if something that we ask you makes you feel scared or worried or sad?

You can tell either me or the other woman you meet with. We are trained to talk to people about their feelings and problems that they are having. We will make a time to speak to you or, if we can't help you, we will put you in contact with someone else who can.

What can you do if you don't understand something or want to know more about this study?

You can ask the person who gave you this form to sign OR you can phone me, René Brandt, on 021-466 7878 or 082 432 6400. I am the person in charge of this study and will be happy to answer your questions or explain anything that you don't understand.

If you want to take part in this study, please sign the attached consent form (you may keep this copy of the information sheet).

Appendix F. Information sheet – Xhosa

UNIVERSITY OF CAPE TOWN

Department of Psychology

IPHEPHA LENKCUKACHA

Molo, ndingu René Brandt. Ndingu gqirha wezenqondo (clinical psychologist) kwakunye nomfundi kwi Dyunivesithi yase Kapa. Ndiqhuba uphando olumalunga nendlela amabhinqa ahlala engingqini yakho athi amelane ngayo ukuba nentsholongwane kaGawulayo kwakunye nendlela abayiphatha ngayo imisebenzi yekhaya kunye nabantwana babo. Ndiyathemba ukuba ngokuthetha namabhinqa, ndingazi ngcono ngamava abo, yaye ndicebise inkokheli zaseluntwini malunga nokunikeza amabhinqa anje ngawe imfuno zengqondo, eziyakuthi zibe luncede ekuphuhliseni izinga lakho lobomu.

Kufuneka wenze ntoni ukuba ugqiba ekuthabatheni inxaxheba kolu phando lwam?

Omnye kwaba bafazi babini osebenza nam, siyakudibana nawe sikubuze imibuzo malunga nokuba bangaphi abantu ohlala nabo, nokuba ngubani ojonga abantwana bakho. Siyakuthi kwakhona sikubuze ukuba ubuziva njani kutsha nje, kwakunye nendlela omelana ngayo nezinto ebomini bakho, nezinye indlela zoncedo olufumanayo kwabanye abantu. Kundwendwelo ngalunye uyakubuzwa imibuzo efanayo ukubona ukuba akukho tshintsho na ukususela kwixesha lokugqibela sidibene. Sifuna nokubona inkcukacha zakho zempilo kunye nokufumanisa ukuba uphile kangakanani nokuba uyawatya amayeza akho. Sizakucela ugqirha wakho asibonise iziphumo zakho zovavanyo lwamajoni omzimba (CD4 count) nobuninzi bentsholongwane (Viral Load).

Singakucela kaphinde ukuba uthethe nathi amamnye amaxesha ambalwa malunga nezinye izinto ezifanayo, ngokubanzi. Singathanda ukuzicishilela ezi ndibano ukwenzela ukuba sizimamele kwaye sicinge into ubuyithethile kwakhona emva koko.

Singakwazi na ukuba konke osixelele kona kube semfihlakalweni yokuba kungaxelelwa mntu?

Ewe. Zonke iinkcukacha esezifumenwe ngophando ukuquka neziphumo zevideo, zizakugcinwa kwikhabhinethi ye ofisini yethu, iyakuba ngamalungu oluvavanyo abazakuba nendlela yokufikelela kuzo. Wonke amalunga ombutho azakukhusela ezinkcukacha zangasese ngokuthembekileyo, futhi abanakukwazi ukuxela igama okanye iicukacha ezixela ngawe nokuba ngumphi na umntu. Le meko siyithatha ngokuxabiselekileyo KAKHULU. Xa sesiyifumene yonke inkcukacha kuwe nakwabanye omama esizakuthi sithethe nabo, sizakuyidibanisa ndawonye ze kungabilula ukuba ubani axelele nokuba ngubani.

Yintoni enokwenzeka xa ungathandi ukuyiphendula lemibuzo okanye ungafuni ukuthatha inxaxheba kwakona?

Akuzokwenzeka nto. Ukukhetha ukungaphenduli mbuzo okanye ungenzinto AKUZUKWENZA NTO embi kuwe. Unokuqhubekeka nokuza ekliniki futhi uzakukwazi ukufumana yonke intlobo yonyango engcono, elungileyo ngokwesiqhelo.

Yintoni onokuyenza xa imibuzo yethu ikwenza woyike okanye uzive ulusizi?

Ungaxelela mna okanye obanye oomama esihlangana nabo. Siqheqheshelwe ukuthetha nabantu ngengxaki nangemvakalelo zabo abathi babe nazo. Sizakwenza ixesha lokuthetha okanye uma singekukwanzi ukukunceda, singakudibanisa nonokukwazi ukukunceda kwakhona.

Yintoni onokuyenza xa kunento ongayiqondiyo okanye ufuna ukwazi banzi ngoluphando?

Ungabuza lomntu okunike ifomu ukuba uyizalise okanye ungatsalela umxeba uthethe noRené Brandt kulenombolo mfonomfono 021 466 7878 okanye kwi cellphone082432 6400. Ndingum mphathi oyintloko yoluphando ndingavuya ukuphendula nokuba nguwuphi na umbuzo okanye ndikuchazele into ofuna ukuyazi okanye ungayiqondiyo.

Xa, ufuna ukuthatha inxaxheba koluphando, nceda uzalise lefomu esisivumelwano esincanyathiselwe kweliphepha lophando.

Appendix G. Questionnaire

AIDS AND SOCIETY RESEARCH UNIT, UNIVERSITY OF CAPE TOWN – WOMEN CAREGIVERS' MENTAL HEALTH PROJECT 2005:

QUESTIONNAIRE

Interviewer name: _____ **Date of interview:** _____

Respondent no: _____ **Group no:** _____

Patient folder no: _____ **Time started:** _____

Time completed: _____ **Duration of interview:** _____

Contact details of participant:

Address (or physical description if no number): _____

_____

Telephone (home/cell): _____ (work): _____

Identify another contact person:

Name: _____ Relationship to participant: _____

Telephone: _____

Can we leave a message for you with this person? ☐

Do you want this person to know that you are taking part in the study? ☐

Note to interviewer re. eligibility:
Is there at least one child less than 18 years old living in the woman's household?
Is the woman the child's primary caregiver? (see page 3 for definition)
The following criteria apply to each group:

Group 1:	HIV negative
Group 2:	HIV positive, not on HAART
Group 3:	HIV positive, recently started HAART
Group 4:	HIV positive, on HAART for six months

Note to interviewer re. administration:

Section A is not for self report. The data must be collected directly from the participant's medical file once consent has been obtained. Sections B-H must be administered directly to the participant. Wherever multiple options are provided, circle the correct response. Note carefully the instructions that certain questions must be omitted for participants in groups 1, 2, 3 or 4.

A. MEDICAL AND ADHERENCE DATA

Note to interviewer re. administration:			
Group 1:	Skip to section B.	Group 3:	A2-A4, A7
Group 2:	A1 only	Group 4:	A2-A12

A1. Current CD4 count

A2. Date commenced HAART:

A3. Baseline CD4 count:

A4. Baseline viral load:

A5. 6-month CD4 count:

A6. 6-month viral load:

dd	*mm*	*yy*			

Antiretroviral medication regimen:

	A7	A8
Drug	Baseline	6months
Stavudine (d4T)		
Lamivudine (3TC)		
Efavirenz (EFV)		
Nevirapine (NVP)		
Didanosine (ddI)		
Zidovudine (AZT)		
Lopinavir/ritonavir (LPV/r)		

Adherence data (%):

A9	A10	A11	A12
4 weeks	8 weeks	12weeks	6 months

Notes: _____

B. PERSONAL AND HOUSEHOLD INFORMATION

Household roster

B1. How many people live in your household? [see definition below]
(Bangaphi abantu abahlala endlini yakho?)

A household is defined as a person or a group of persons who live together at least four nights a week at the same address, eat together and share resources. To be counted as living in the household, a person must spend at least four nights a week on average in the household.

Note to interviewer re. administration:

Please complete the rest of the 'Household roster' section (B2-B17) in the following order:

1. Ask the participant questions B5-6 and B8-13 about herself [i.e. complete row 1 of the table on p. 4]. Codes A-D needed to complete the table are attached at the end of this questionnaire
2. Ask the participant questions B14-17 about herself [see below].
3. Ask the participant questions B2-13 about the other members of her household [i.e. complete the remaining rows of the table on pp. 4 and 5].

Next proceed to the next section on 'Non-resident biological children' (B18-B28) on p. 7.

The primary caregiver is defined as the person mainly responsible for the day-to-day care of a child (including feeding, bathing, playing with, monitoring and transporting).

B14. What is the language spoken most often in your household?
(Leliphi ilwimi elithethwa rhoqo ekhayeni lakho?)

Xhosa *(isiXhosa)*	1
English *(isiNgesi)*	2
Afrikaans *(iAfrikaans)*	3
Other (specify) *(Enye (chaza))*	4

B15. Do you currently have a partner who is not a member of your household?
(Ingaba unalo iqabane elingelo lungu lekhaya lakho?)

Yes *(Ewe)*	1
No *(Hayi)*	2
Not applicable *(Ayingeni)*	NA

B16. Do you have any post-school qualifications?
(Ingaba unayo na imfundo enomsila?)
If no, skip to B.18.

Yes *(Ewe)*	1
No *(Hayi)*	2

B17. If yes, please specify *(chaza)*: _____

	B2	B3	B4	B5	B6	B7	B8	B9	B10	B11	B12	B13
No	First name *(igama lakho)*	Relationship to participant *(Ubudlelwa-ne nomthathi nxaxheba)*	Sex *(Isini)*	Date of birth *(Isaka lokuzalwa)*	Age *(Iminyaka)*	If less than 18yrs. is the participant the primary caregiver? [see def. on p. 3] *(Ukuba iminyaka ingaphantsi kwe18, ingaba umthathi nxaxheba ngoyena mongi?)*	What is the highest grade the person passed? *(Ibanga lezemfundo oluphumeleleyo?)*	What is the person's current employment status? *(Ithini imo yalomntu ngokomsebenzi?)*	What type of grant does the person receive? *(Loluphi uncedo lomntu alufumana kurhulumente)*	Briefly describe the kind of work the person does. *(Chaza uhlobo lomsebenzi owenziwa ngulomntu.)*	Approximately how much money does the person take home every month, including grants? *(Ngokuqikelela yimalini abuyanayo lomntu ekhaya ngenyanga, nkuqika inkamnkam?)*	Does the person contribute to paying household expenses? *(Ingaba lomntu uyancedisa ekuhlawuleni amatyala ekh ya?)* 1 = Yes, a lot *(Ewe, kakhulu)* 2 = Yes, a little *(Ewe, kancinci)* 3 = No *(Hayi)*
		Codes A	M F	dd/mm/yy	Mnths/ Yrs	Yes No NA	Codes B	Codes C	Codes D		Rands	
1	[redacted]	[redacted]	1 (2)			[redacted]						1 2 3
2			1 2			1 2 NA						1 2 3
3			1 2			1 2 NA						1 2 3
4			1 2			1 2 NA						1 2 3

B2	B3	B4	B5	B6	B7	B8	B9	B10	B11	B12	B13
First name *(igama lakho)*	Relationship to participant *(Ubudlelwa-ne nomthathi nxacheba)*	Sex *(Isini)*	Date of birth *(Usuku lokuzalwa)*	Age *(Iminyako)*	If less than 18yrs, is the participant the primary caregiver? [see def. on p. 3] *(Ukuba iminyaka ingaphantsi kwe18, ingaba umthathi nxacheba ngovena mongi?)*	What is the highest grade the person passed? *(Ibanga lezemfundo oluphumelele-vo?)*	What is the person's curren: employ-ment status? *(Ithini imo yalomntu ngokomse benzi?)*	What type of grant does the person receive? *(Lalupi uncedo lomntu alufumana kurihlumen te)*	Briefly describe the kind of work the person does. *(Chaza uhlobo lomsebenzi owenziwa ngulomntu.)*	Approximately how much money does the person take home every month, including grants? *(Ngokuqikelela vinalini abuyanayo lomntu ekhaya ngenyanga, ukuquka inkam-nkan')*	Does the person contribute to paying household expenses? *(Ingaba lomntu uyancedisa ekuhlawuleni amatyala ekhaya?)* 1 = Yes, a lot *(Ewe, kakhulu)* 2 = Yes, a little *(Ewe, kancinci)* 3 = No *(Hayi)*
	Codes A	M F	dd/mm/yy	Muths/ Yrs	Yes No NA	Codes B	Codes C	Codes D		Rands	1 2 3
		1 2			1 2 NA						1 2 3
		1 2			1 2 NA						1 2 3
		1 2			1 2 NA						1 2 3
		1 2			1 2 NA						1 2 3

No	B2 First name *(igama lakho)*	B3 Relationship to participant *(Ubudlelwa-ne nomthathi nxaxheba)*	B4 Sex *(Isini)*	B5 Date of birth *(Isuku lokuzalwa)*	B6 Age *(Iminyaka)*	B7 If less than 18yrs, is the participant the primary caregiver? [see def. on p. 3] *(Ukuba iminyaka ingaphantsi kwe18, ingaba umtiathi nxaxheba ngoyena nongi?)*	B8 What is the highest grade the person passed? *(Ibanga lezemfundo aluphumelele-yo?)*	B9 What is the person's current employ-ment status? *(Ithini imo yolomntu ngokomse benzi?)*	B10 What type of grant does the person receive? *(Loluphi uncedo lomntu alufumana kurhulumen te)*	B11 Briefly describe the kind of work the person does. *(Chaza ukuloko iomsebenzi owenziwa ngulomntu.)*	B12 Approximately how much money does the person take home every month, including grants? *(Ngokuqikelela yimalini abuyamayo lomntu ekhaya ngenxaniga. ukuqaka inkam-nkam?)*	B13 Does the person contribute to paying household expenses? *(Ingaba lomntu uyancedisa ekuhlawuleni amatyala ekhaya?)* 1 = Yes, a lot *(Ewe, kakhulu)* 2 = Yes, a little *(Ewe, kancinci)* 3 = No *(Hayi)*
		Codes A	M F	dd/mm/yy	Mths Yrs	Yes No NA	Codes B	Codes C	Codes D		Rands	
9			1 2			1 2 NA						1 2 3
10			1 2			1 2 NA						1 2 3
11			1 2			1 2 NA						1 2 3
12			1 2			1 2 NA						1 2 3

n-resident biological children

8. Do you have any biological children who do not currently live in your household? [Include only children less than 18 years]. *(Ingaba unabo abantwabo bakho abangahlali ekhayeni lakho? (bandakanya abantwana kuphela abaneminyaka eyio 18 nangaphantsi)).* If no, skip B29.

Yes *(Ewe)*	1
No *(Hayi)*	2

19. How many non-resident biological children do you have? *(Bangaphi abantwana abangahlali nawe bakho onabo?)*

Please provide details by completing a row in the table below for each child.

	B20	B21	B22	B23	B24	B25	B26	B27	B28
o	Sex *(Isini)*	Date of birth *(Umhla wokuzalwa)*	Age *(Iminyaka)*	Highest grade passed *(Ibanga alifundayo ngoku okanye ibanga elaphezulu lezemfundo olifumeneyo)*	Place of residence *(Indawo ohlala kuyo)*	Person with whom they live *(Umntu ohlala naye)*	Has this child ever lived with the participant? *(Ingaba lomntwana wakhe wahlala nomthabathi nxaheba?)* If no, skip to B29. If yes, complete table.	When was the last time? *(Ugqibele nini?)*	Why did the child move from your household? *(Wahambela nini umntwana endlini yakho?)*
	M F	dd/mm/yy	years	Codes B	Town, province *(Idolophu, iphondo)*	Codes A	Yes No	mm/yy	
	1 2						1 2		
	1 2						1 2		
	1 2						1 2		
	1 2						1 2		

Household characteristics

B29. What is the household's main source of water? *(Ikhaya lixhomekeke kwintoni ngokufumana amanzi?)*

Outside tap only *(Impompo engaphandle)*	1
Inside tap *(Impompo engaphakathi)*	2

B30. What kind of toilet does your household have access to?
Luluphi uhlobo lwezindlu zangasese ikhaya elifikelela kulo?

Inside flush toilet *(Indlu yangasese engaphakathi etsalwayo)*	1
Outside toilet in your yard *(Indlu yangasese esebaleni lakho)*	2
Outside toilet not in your yard *(Indlu yangasese engekho sebaleni lakho)*	3

B31. How many rooms does your household occupy in their dwelling? [Include bedrooms and living rooms, as well as backyard shacks if they are part of the household. Exclude bathrooms and toilets]. *(Mangaphi amagumbi asetyenziswa likhaya lakho endlini yabo. (Bandakanya amagumbi okulala nawokuhlala,kwakunye namatvotyombe angenva ukuba avixalenye yekhaya. Shiya amagumbi okuhlambela nawangasese.))*

Does your household have the following items in working condition?
Ingaba ikhaya lakho linazo ezizinto zilandelayo ngendlela esebenzayo?)

		Yes *(Ewe)*	No *(Hayi)*
B32.	Radio *(umoumabo-thulo)*	1	2
B33.	Television *(umabona-kude)*	1	2
B34.	Refrigerator *(isikhandisi)*	1	2
B35.	Telephone in the dwelling *(imfono-mfono endlini)*	1	2
B36.	Cellphone *(imfono-mfono ephathwayo)*	1	2

B37. Does your household receive a regular food parcel (e.g. weekly or monthly) from a church, charity, clinic or a school feeding programme? [Do not include food received from friends or relatives on an occasional basis]. *(Ingaba ikhaya lakho lifumana inxaso yokutya rhoqo (e.g. ngeveki okanye ngenyanga) kvicawe, ngesisa,ekliniki okanye kwinqubo yokondla esikolweni? (sukubandakanya ukutya okufumana kubahlobo okanya kwizizalwane ngamaxesha athile))*

Yes *(Ewe)*	1
No *(Hayi)*	2

B38. Does your household regularly receive food, clothing or other items which household members need from neighbours, friends, relatives? (e.g. about once a month) *(Ingaba ikhaya lakho lifumana ukutya rhoqo, impahla okanye eziaye izinto ezithi zibeyinnfaneko kumalungu ekhaya ezivela komelwane, abahlobo, kwakunye nezizalwane? (Malunga nakanye ngeveki))*

Yes *(Ewe)*	1
No *(Hayi)*	2

Household characteristics

B29. What is the household's main source of water? *(Ikhaya lixhomekeke kwinoni ngokufumana amanzi?)*

Outside tap only *(Impompo engaphandle)*	1
Inside tap *(Impompo engaphakathi)*	2

B30. What kind of toilet does your household have access to? *Luluphi uhlobo lwezindlu zangasese ikhaya eliţikelela kulo?*

Inside flush toilet *(Indlu yangasese engaphakathi etsalwayo)*	1
Outside toilet in your yard *(Indlu yangasese esebaleni lakho)*	2
Outside toilet not in your yard *(Indlu yangasese engekho sebaleni lakho)*	3

B31. How many rooms does your household occupy in their dwelling? [Include bedrooms and living rooms, as well as backyard shacks if they are part of the household. Exclude bathrooms and toilets]. *(Mangaphi amagumbi asetyenziswa likhaya lakho endlini yabo. (Bandakanya amagumbi okuiala nawokuhlala,kwakunye namatyotyombe angemva ukuba ayinxalenye yekhaya. Shiya amagumbi okuhlambela nawangasese.))*

Does your household have the following items in working condition? *(Ingaba ikhaya lakho linazo ezizinto zilandelayo ngendlela esebenzayo?)*

		Yes *(Ewe)*	No *(Hayi)*
B32.	Radio *(umoya-tholo)*	1	2
B33.	Television *(umabona-kude)*	1	2
B34.	Refrigerator *(isihandisi)*	1	2
B35.	Telephone in the dwelling *(imfono-mfono endlini)*	1	2
B36.	Cellphone *(imfono-mfono ephathwayo)*	1	2

B37. Does your household receive a regular food parcel (e.g. weekly or monthly) from a church, charity, clinic or a school feeding programme? [Do not include food received from friends or relatives on an occasional basis]. *(Ingaba ikhaya lakho lijumana inxaso yokutya rhoqo (e.g. ngeveki okanye ngenyanga) kwicawe, ngesisa,ekliniki okanye kwinqibo yokondla esikolweno? (sukubandakanya okutya okufumana kubahlobo okanya kwizizalwane ngamaxesha athile))*

Yes *(Ewe)*	1
No *(Hayi)*	2

B38. Does your household regularly receive food, clothing or other items which household members need from neighbours, friends, relatives? (e.g. about once a month) *(Ingaba ikhaya lakho lijumana okuya rhoqo, impahla okanye ezinye izinto ezithi zibeyimfuneko kumalungu ekhaya ezivela komeiwane, ubahlobo, kwakunye nezizalwane? (Malunga nakanye ngeveki))*

Yes *(Ewe)*	1
No *(Hayi)*	2

B39. How often do household members go without food?
(Iba iitheuba elingakanani abantu ekhayeni lakho abathi bahlale ngaphandle kolutya?)

Often *(Rhoqo)*	1
Sometimes *(Ngamaxesha athile)*	2
Rarely *(Kunqabile)*	3
Never *(Zange)*	4

B40. How regular is your household's total income? *(Kungangaphi ikhaya lakho lifumana ingeniso ephelele yonke?)* [grants included]

Very irregular – *(Ngokungesosiqhelo kakhulu)*	No pattern to how much we get and when. Often we might not get anything. *(Akukho ngqgo wokokuba sifumana kangakanani nanini. Ngamaxesha athile asifumani nto.)*	1
Irregular *(Ngokungekho siqhelweni)*	We usually get some money each month, but the time and amount varies. *(Sidla ngokufumana imali nyanga nganye, kodwa ixesha nesiqingatha simyuka-sisehla.)*	2
Regular – *(Ngokwesiqhelo)*	We get some money at the same time each month or week, but the amount varies. *(Sifumana imali ngaxesha linye qho ngenyanga okanye ngeveki, kodwa isixa siyaka-sisehla.)*	3
Very regular – *(Ngokwesiqhelo kakhulu)*	We get the same amount of money each month or week at the same time. *(Sifumana isixa esifanayo semali nyanga nganye okanye ngeveki ngexesha elinye.)*	4

Note to interviewer: B41-45 to be completed from household roster.

B41. Average monthly household income [sum of responses to B12]:

B42. Number of persons in household [check response to B1 & household roster]:

B43. Number of adults in household (18 years or older):

B44. Number of older children in household (13-17 years):

B45. Number of young children in household (0-12 years): _____

Notes: _____

C. CAREGIVING INFORMATION

Unpaid care to children in the household

C1. Do you provide care for any children (less than 18 years) who live in your household? *(Unabo abantwana obujongayo ohlala nabo endlwini abanga phantsi kweminyaka esibhozo?)*

Yes *(Ewe)*	1
No *(Hayi)*	2

C2. How many children do you care for? *(Bangaphi abantwana obakhathalele?)*

Please provide details by completing a row in the table below for each child.

	C3	C4	C5
No.	Recipient of care: who *(ngubani)*	Nature of care: when *(nini)*	what *(yintoni)*
	Line no. from household roster	Codes E	Codes F
1			
2			
3			
4			
5			

C6. How many other people, regardless of their age and where they live, help look after the children who live in your household (e.g. care for and supervise)?
(Bangaphi abantu, nokuba bahlala phi okanye bangakanani, abancedisa (unzekelo, ukukhathalela kunye nokujonga) ukukoncedisa abantwaneni abahlala ekhayeni lakho?)

Please provide details by completing a row in the table below for each child-carer pair.

	C7	C8		C9	C10	C11
No.	Recipient of care: who *(ngubani)*	Provider of care: Relationship to participant *(Ubudlelwane nomthathi nyacheba)*		Line no. from household roster if applicable	Nature of care: when *(nini)*	what *(yintoni)*
	Line no. from household roster	Codes A			Codes E	Codes F
1						
2						
3						
4						
5						
6						
7						

8				
9				
10				
11				
12				

C12. NOT FOR GROUP 1:
How do you think your being HIV positive has affected your children, or other children in your household? *(Ingaba ucinga ukuqala kwakho sesi sifo sika gawulayo sibachaphazela njani abantwana bakho okanye ohlala nabo edlini?)*
[If difficulty responding, ask whether there have been any concrete/practical changes in the participant's caregiving role OR any emotional changes or shifts in the relationship.]

C13. NOT FOR GROUPS 1 AND 2:
How do you think your being on antiretroviral therapy has affected your children, or other children in your household? *(Ingaba ucinga ukuba ukutya kwakho iamayeza kubachaphazela njani abantwana bakho okanye ohlala nabo edlini?)*

Note to interviewer: C14-C16 to be completed from household roster.

C14.	Number of children in the household who are the participant's biological children:	
C15.	Number of children in the household who are not the participant's biological children:	
C16	Number of children in the household for whom the participant is the primary caregiver [B7]:	

Unpaid care to non-biological children outside the household

C17. Do you provide care for any children (less than 18 years) who do not live in your household? *(Bakhona abantwana abafongayo abangaphantsi iminyaka eyi 18 ekafoneka ubanike uncedo lohlaho olunjile bebe bengahlali kulomzi wakho?)*
If no, skip to C25.

Yes *(Ewe)*	1
No *(Hayi)*	2

C18. How many children do you care for? *(Bangaphi abantwana obakhathalele?)*

Please provide details by completing a row in the table below for each child.

No	C19 Who *(ngubani)*: Relationship to participant *(Ubudlelwane nomthathi nxaxheba)*	C20 Sex *(Isini)*	C21 Age *(Iminyaka)*	C22 Place of residence *(Indawo yokuhlala)*	C23 Nature of care: When *(nini)*	C24 What *(ntoni)*
	Codes A	M F	Months, years	1 – household *(umzimba)* 2 – not in household, but in neighbourhood *(abangekho kulomzi kodwa bongomelwane)* 3 – outside neighbourhood *(abangaphandle konodwane)*	Codes E	Codes F
1		1 2		1 2 3		
2		1 2		1 2 3		
3		1 2		1 2 3		
4		1 2		1 2 3		

Unpaid care to adults in- and outside the household

C25. Do you provide significant amounts of special care to any adults (18 years or older) (for example, because they are physically or mentally disabled, or elderly)? *(Bakho abantu obadala (iminyaka eyi 18 angaphezulu) ekufuneka ubanike uncedo olukhethe (umzekelo, kuba bengakwazi ukuzenzela nto ngemo nange ngqondo, okanye yobudala?)*

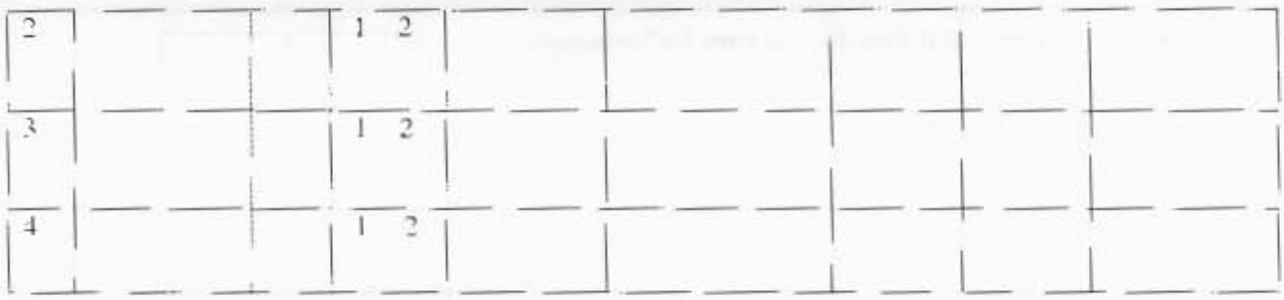
Yes *(Ewe)*	1
No *(Hayi)*	2

If no, skip to section D.

C26. How many adults do you care for? *(Bangaphi abadala obakhathalelayo?)*

Please provide details by completing a row in the table below for each adult.

No	C27 Who *(ngubani)*: Relationship to participant *(Ubudlelwane nomthathi nxaxheba)*	C28 Sex *(Isini)*	C29 Age *(Iminyaka)*	C30 Line no. in household roster if applicable	C31 Nature of care: When *(nini)*	C32 What *(ntoni)*	C33 Reason for care *(Isizathu sokubakhathi alela)*
	Codes A	M F	Months, years		Codes E	Codes F	
1		1 2					



Notes:

D. HEALTH-RELATED INFORMATION

General health information: Women, their partners and their households

D1. On a scale of 1 to 10, if 10 is the healthiest you have felt in your life, what score would you give to how you feel at the moment? *(Kuthotho lwamaqondo okulinganisa kususela kwesinye kuya eshumini, ukuba ishumi yeyona ndlela iphilileyo owake waziva ngayo ebomini, leliphi inqaku onokuzinika lona ukubona kalisa indlela owaziva ngayo xa uqala lamachiza kaGawulayo?)*
[Circle the correct response]

1	2	3	4	5	6	7	8	9	10

D2. Approximately how much time in total have you spent overnight in hospital in the past six months? *(Ngamafaphi,xa uqikelela zingaphi intsuku ngokupheleleyo owazichithela nobusuku esibhedlele kwinyanga ezintandathu ezigqithileyo?)*

None *(akukho nalinye ixesha)*	1
Less than a week *(Ngexesha elingaphantsi kweviki)*	2
Less than a month *(Ngexesha elingaphantsi kwenyanga)*	3
1-3 months *(enyangeni enye kuyakweziinathu)*	4
More than 3 months *(Ngaphezu kwenyanga ezintathu)*	5

D3. Are you currently being treated for TB?
(Ingaba ngoku ufumana unyango lweSifo sephepha?)
If yes, skip to D5.

Ewe / *Yes*	1
Hayi / *No*	2

D4. If no, have you been treated for TB in the last year?
(Xa usithi hayi, ingaba wake wanyangelwa iSifo sephepha kunyaka odlulileyo?)

Ewe / *Yes*	1
Hayi / *No*	2

D5. Do you have any other chronic [physical] health problems?
(Ingaba unayo enye igxaki yezempilo [ngokomzimba] ebalaseleyo okungapheliyo?)
If no, skip to D7.

Ewe / *Yes*	1
Hayi / *No*	2

D6. If yes, please specify *(Ukuba ewe, chaza)*

High blood pressure *(uxinzelelo lwegazi lemizwai*	1
Asthma *(umbefu okanye isifo sofuba)*	2
Arthritis *(isifo samathambo)*	3
Diabetes *(isifo seswekile)*	4
Heart condition *(isifo senhliziyo)*	5
Physical disability (e.g. multiple sclerosis) *(Ukwenzakaliswa komzimba (umzekelo, isiphindo sesifo sokuqina kwemithambo))*	6
Other (specify) *(Enye (chaza))*	7

D7. Have you ever had a psychological problem for which you either received or needed treatment (medication or counselling)? *(Ingaba wakhe wane ngxaki yokugula ngengqondo owathi wafumana okanye wafuna unyango (amayeza okanye ukucetyiswa)?)* If no, skip to D9.

Ewe / *Yes*	1
Hayi / *No*	2

D8. If yes, specify *(Ukuba ewe, chaza)*:

8.1 Nature of problem *(Uhlobo wengxaki)*

8.2 When treated *(ngexesha lwonyango)*

As a child (less than 18 years) *(Njengomntwana (ongaphantsi kweminyaka elishumi nesibhozo))*	1
As an adult, before being diagnosed with HIV *(Njengomntu okhulile, ngaphambi koxilongo lwesifo setsholongwane kagawulayo)*	2
As an adult, after being diagnosed with HIV *(Njengomntu okhulile, emva koxilongo lwesifo setsholongwane kagawulayo)*	3
Other (specify) *(Enye (chaza))*	4

8.3 Nature of treatment *(uhlobo lwonyango)*
[multiple responses possible]

Counselling *(udlwana ndlebe nomcebisi)*	1
Hospitalised *(ukulaliswa esibhedlele)*	2
(Western) medication *(lwasentshonalanga) unyango)*	3
Consulted sangoma, including for traditional medicine *(ukusebenzisa amayeza amasiko nezithethe)*	4

D9. Does any member of your household have a serious health problem or attend a clinic regularly to receive treatment? *(Ukhona umntu apha endlini yakho okhathazwa yimpilo okanye ofumana iinyango eclinic rhoqo?)*

Ewe / *Yes*	1
Hayi / *No*	2

If yes, please provide details in the table below.

No.	D10 Line no. in household roster	D11 Nature of problem						D12 (If marked 2 – i.e. HIV+) Nature of treatment: ARVs			D13 Support group		
		1 – Mental or physical disability *(oqula ngengqondo okanye okhubazekileyo ngokomzimba)* 2 = HIV/AIDS 3 = Arthritis *(isifo samathambo)* 4 = Heart condition *(isifo sentliziyo)* 5 = Other (specify) *(Enye (chaza))*					Specify	Yes	No	NA	Yes	No	NA
1		1	2	3	4	5		1	2	3	1	2	3
2		1	2	3	4	5		1	2	3	1	2	3
3		1	2	3	4	5		1	2	3	1	2	3
4		1	2	3	4	5		1	2	3	1	2	3
5		1	2	3	4	5		1	2	3	1	2	3

If you have a current partner who does not live in your household [answered yes to B15], answer the questions in the table below (D14-D16). If not, skip to D17.

		Yes *(Ewe)*	No *(Hayi)*	Not sure *(Awaqiniseki)*
D14.	Is your partner HIV positive? *(Ingaba iqabane lakho line Ntsholongwane kaGwadayo?)* If no, skip to section E.	1	2	3
D15.	Does your partner attend an HIV related support group on a regular basis? [see D20 for definition] *(Ingaba iqabane lakho liyazihamba intlangano zoncedo (support groups) zeNtsholongwane kaGwadayo rhoqo?)*	1	2	3
D16.	Is your partner receiving antiretroviral therapy? *(Inagab iqabane lakho lifumana amachiza entsholongwane kaGwadayo?)*	1	2	3

HIV-related information

Note to interviewer re. administration:		
Group 1:	Skip to section E.	Group 3: Stop at D31.
Group 2:	Stop at D27	Group 4: Ask all questions

D17. How did you find out you were HIV positive? *(Uvenjani ukuba unentsholongwane kagawulayo?)*

D18. When did you find out you were HIV positive?
(Wazi nini ukuba une Ntsholongwane kaGawulayo?)

mm	*yy*

D19. What was your most recent CD4 cell count?
(Zithini iziphumo zakho zovavo nyo zakutsha nje?)

Note to interviewer for D19: For Group 3 this should be their CD4 when they started HAART, and for Group 4 their 6-month CD4 cell count.

D20. Do you attend an HIV related support group on a regular basis (i.e. attend either a weekly or monthly group, as available, only missing sessions under special circumstances)?
(Uyazihamba intlangano zonxedo (support groups) zeNtsholongwane kaGawulayo rhoqo (uzihamba ngeveki okanye ngenyanga, xa zikhona, uphosa ezithile phantsi kwemeko ezibalulekileyo)?)

Yes *(Ewe)*	1
No *(Hayi)*	2

D21-D27 Who have you disclosed your HIV status to and where do they live? Also indicate when and why you disclosed to them. *(Uchazele bani ngale ntsholongwane kagawulayo bahlalaphi xela ukuba ubaxelele nini bekutheni ukuze ubaxelele?)*
(Complete table on next page)

No	D21 Who (ngubani): Sex (Isini) M	D21 Who (ngubani): Sex (Isini) F	D22 Age (Iminyaka) Yrs	D23 Relationship to participant (Ubudlelwane nomthathi nxasheba) Codes A	D24 Place of residence (Indawo yokuhlala) 1 = household (umzimba) 2 = not in household, but in neighbourhood (abangekho kulomzi kodwa bengomelwane) 3 = outside neighbourhood (abangaphandle komelwane)	D25 Line no. in household roster if applicable	D26 when (nini) mm/yy	D27 Details of disclosure: primary reason for disclosure (nika izizathu zokuzichaza kwakho) 1 – to share your problem (ukwabela ngenxaki) 2 – to protect someone from possible infection (ukukhusela umntu ongasuleleki izifo) 3 – to get someone's help (e.g. with treatment) (ukufumana umuntu oluncedo) 4 – to educate someone about HIV (ukufundisa umntu ngesifo sika gawulayo) 5 – to decrease stigma (ukuncitshiswa kwendlela abantu abangawulawo abajongwa ngayo) 6 – other (specify) (enye echaza)
1	1	2			1 2 3			1 2 3 4 5 6
2	1	2			1 2 3			1 2 3 4 5 6
3	1	2			1 2 3			1 2 3 4 5 6
4	1	2			1 2 3			1 2 3 4 5 6
5	1	2			1 2 3			1 2 3 4 5 6
6	1	2			1 2 3			1 2 3 4 5 6
7	1	2			1 2 3			1 2 3 4 5 6
8	1	2			1 2 3			1 2 3 4 5 6
9	1	2			1 2 3			1 2 3 4 5 6

D28. When did you start antiretroviral therapy?
(Uqale nini ukutya amayeza ka gawulayo?)

mm	yy

D29. Did you feel positive about starting antiretrovirals?
(Uziva esemdleni ngokuqalisa amachiza kaGawulayo?)

Yes *(Ewe)*	1
No *(Hayi)*	2
Not sure *(Awuqinisekanga)*	3

D30. Have you had to change your ARV regimen at all since you started?
(Ibikhe yakhonana intlaneko yokuba ulungisha duhloho lamayeza oko ubuwaqalile?)

Yes *(Ewe)*	1
No *(Hayi)*	2

D31. Have you experienced any of the following side-effects from the ARVs recently?
(Akukhanye ubenangxaki yokuvukwa zizigulo oko ubuqale ukutya lamayeza?)

Note to interviewer: For Group 3 this should be since they started ARVs, and for Group 4 in the month prior to interview.

		Yes *(Ewe)*	No *(Hayi)*
D31.1	Stomach complaints (e.g. nausea, vomiting, diarrhoea) *(Awukhe ubunazo ingxaki zesisu (umzekelo isiyezi, ukugabha, ukuhombisa))*	1	2
D31.2.	Headaches *(intloko)*	1	2
D31.3.	Fevers, chills, sweats *(umfiwane, ukubila, ukubanengqele)*	1	2
D31.4.	Unwanted weight loss *(umzuzuva omphayo ongavumiyo)*	1	2
D31.5.	Sexual problems (e.g. loss of interest, lack of satisfaction) *(ingxaki zesondo (umzekelo ukuphela umdla ukungenelisi))*	1	2
D31.6.	Skin problems (e.g. rash) *(ingxaki zofele (umzekele amaqhakuva))*	1	2
D31.7.	Muscle aches and joint pain *(Izilimo ezibuhlungu kunye namalungu ohuhlungu)*	1	2
D31.8.	Pain, numbness or tingling in the hands and feet *(Intlungu, amalungu ezandla atyhafuyo nawe nyawo)*	1	2
D31.9.	Feeling dizzy or light-headed *(uziva unesiyezi)*	1	2
D31.10.	Hepatitis *(ukhe ubenama dyungudyu)*	1	2
D31.11	Vivid dreams *(amaphupho amabi)*	1	2
D31.12	Feeling tired/exhausted *(uziva udiniwe)*	1	2
D31.13	Trouble remembering *(ukuba nengxaki yokukhumbula)*	1	2
D31.14	Other (specify) *(Enye (chaza))*	1	2

D32. Did you experience any of the following side-effects in the first two weeks after starting antiretroviral therapy?
(Akukhanye ubenengxaki na yobuba nezizigulo zilandelayo kwezi veki zimbini zokuqala uvityo lamayeza?)

		Yes *(Ewe)*	No *(Hayi)*
D32.1	Stomach complaints (e.g. nausea, vomiting, diarrhoea) *(Awukhe ubunazo ingxaki zesisu (umzekelo isivezi, ukugabha, ukuhambisa))*	1	2
D32.2	Headaches *(intloko)*	1	2
D32.3	Fevers, chills, sweats *(infevvane, ukubila, ukubanengqele)*	1	2
D32.4	Unwanted weight loss *(umzimba onatjhaya ongawufuniwa)*	1	2
D32.5	Sexual problems (e.g. loss of interest, lack of satisfaction) *(Ingxaki zesondo (umzekelo ukuphela umdla okungeneli))*	1	2
D32.6	Skin problems (e.g. rash) *(ingxaki zofele (umzekele ondaphakovat))*	1	2
D32.7	Muscle aches and joint pain *(Izihlunu ezibuhlungu kunye namalunyu abuhlungu)*	1	2
D32.8	Pain, numbness or tingling in the hands and feet *(buhlungu, umalunga ezandla atyhafayo nawe nyawo)*	1	2
D32.9	Feeling dizzy or light-headed *(uziva unesivezi)*	1	2
D32.10	Hepatitis *(ukhe ubenama dvungudva)*	1	2
D32.11	Vivid dreams *(onaphupho ambi)*	1	2
D32.12	Feeling tired/exhausted *(uziva udiniwe)*	1	2
D32.13	Trouble remembering *(ukuba nengxaki vokulibala)*	1	2
D32.14	Other (specify) *(Enye (chaza))*	1	2

D33. On a scale of 1 to 10, if 10 is the healthiest you have felt in your life, what score would you give to how you felt when you started ARVS? *(Kuthotho lwamaqondo okulinganisa kususela kwesinye kuya eshumini, ukuba ishumi yeyona ndlela iphilileyo owake waziva ngayo ebomini, lelipi ingaka onokuzinika lona ukubona kalisa indlela owaziva ngayo xa uqala iamachiza kaGawulayo?)*
[Circle the correct response]

1	2	3	4	5	6	7	8	9	10

Notes:_____

E. COPING STRATEGIES (BRIEF COPE)

These items deal with ways you've been **coping with the stress in your life recently**. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know **to what extent you've been doing what the item says**. How much or how frequently. Don't answer on the basis of whether it seems to be working or not - just whether or not you're doing it. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

(Ezi zinto zijongene nedlela nokokuba ukwaza ukumelana nobunzima ebomini bakho kutsha nje, kwakunye nedlela omelana ngayo nezinto ebomini bakho. nezinye idlela zonedo olufumanayo kwabanye abantu. Zininzi iindlela zokujongana neengxaki. Lowcinibi wethu uzakubuza ukuba intoni onokuyenza ukujongana nezigxaki. Kucacile ukuba ngokwesiqhelo, abantu banendlela, nge'ndlela zokwenza izinto. Ndinomdla wokuva ukuba ziziphi inzame ozenzileyo ukumelana nemeko yakho. Umbuzo ngaanye uchaza iindlela ethile yokuziphatha. Ndifuna ukwazi banzi kululdu ngalunye ukuba uzilandela kangakanani izinto ezibuzwayo ebomini bakho. Ungaphenduli phezu kwento yokuba iyakusebenzela okanye ayikusebenzeli. Phendula ukuba uyayenza okanye awuyenzi. Zama ukwehiuda hlula iingcinga nganye. Nceda wenze iimpendulo zakho ezinyanisekileyo njengoko usazi.)

Circle one number on each line *(yenza isangqa kwinani kwanga adwelisiweyo)*:

1 = I haven't been doing this at all *(zange ndiyenza lento)*
2 = I've been doing this a little bit *(bendiyenza kancinci)*
3 = I've been doing this a medium amount *(bendiyenza ngeloxesha)*
4 = I've been doing this a lot *(bendiyenza gqithu)*

E1.	I've been turning to work or other activities to take my mind off things. *(Bendiphanobukela emsebenzini ndiphangele okanye ndenze ezinye izinto ukuba ndingayicingi lento.)*	1	2	3	4
E2.	I've been concentrating my efforts on doing something about the situation I'm in. *(Ndiye ndazinikezela ngomdla wam wonke ukwenza enabako kwimeko yam.)*	1	2	3	4
E3.	I've been saying to myself "this isn't real". *(Bendizivelela ukuba "ayikho lento".)*	1	2	3	4
E4.	I've been using alcohol or other drugs to make myself feel better. *(Bendisebenzisa utywala neziyobisi ukuze ndizive ndibetele.)*	1	2	3	4
E5.	I've been getting emotional support from others. *(Bendifumana uncedo navelwano kwabanye kwiingxelebelelo.)*	1	2	3	4
E6.	I've been giving up trying to deal with it. *(Ndiye ndaphokezela ukumelana nemeko endikuyo.)*	1	2	3	4
E7.	I've been taking action to try to make the situation better. *(Ndizame ukuzenzela imizamo yokujonganga nokwenzabhetele imeko yam.)*	1	2	3	4
E8.	I've been refusing to believe that it has happened. *(Bendisoloko ndisala ndingavumi ukuba ndevikholetwe ukuba yenzekile.)*	1	2	3	4
E9.	I've been saying things to let my unpleasant feelings escape. *(Benditthetha izinto ezibangela imeko yam emaxongo ukuba idlule okanye ndizive ndivilibele.)*	1	2	3	4
E10.	I've been getting help and advice from other people. *(Bendifumana uncedo neengcebiso kwabanye abantu.)*	1	2	3	4

E11.	I've been using alcohol or other drugs to help me get through it. *(Bendisebenzisa utywala neziyobisi ngenjongo zokudlula kwimeko endikuyo.)*	1	2	3	4
E12.	I've been trying to see it in a different light, to make it seem more positive. *(Bendizama ukuyiqwalasela ngeliso elahlukileyo, ukuze ndiyijonge ngendlela enika ithemba.)*	1	2	3	4
E13.	I've been criticising myself. *(Bendizi gxeka mna.)*	1	2	3	4
E14.	I've been trying to come up with a strategy about what to do. *(Bendizama ukufumana iceba elinobuchule lokuba ndenze njani.)*	1	2	3	4
E15.	I've been getting comfort and understanding from someone. *(Bendifumana ukuphathwa kakuhle kanye nolonwabo kunye nauma.)*	1	2	3	4
E16.	I've been giving up the attempt to cope. *(Ndiye ndanikezela kwinzame zokumelana nemeko.)*	1	2	3	4
E17.	I've been looking for something good in what is happening. *(Bendikhangela into entle kulento yenzekayo.)*	1	2	3	4
E18.	I've been making jokes about it. *(Bendisenza intlekisa ngayo.)*	1	2	3	4
E19.	I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping. *(Bendenza izinto zokuba ndicinge kancinci ngalengxaki, njengokuya kwibhayisikobhio, ndijonge umabonakude, ndifunde, ndibekumvandlwa ndilale okanye ndiyokuthenga evenkileni.)*	1	2	3	4
E20.	I've been accepting the reality of the fact that it has happened. *(Ndaye ndiahamkela ubukho okanye ubunyani balento ndinoyo okokubayenzeka.)*	1	2	3	4
E21.	I've been expressing my negative feelings. *(Bendibonakalisa ukungaphathekikakuhle.)*	1	2	3	4
E22.	I've been trying to find comfort in my religion or spiritual beliefs. *(Bendizama ukufumana idonwabo enkolweni (umzekelo njengenkolo yezinyanya, masilamsi, amaRasta nill) okanye kwinkolo yomphefumlo.)*	1	2	3	4
E23.	I've been trying to get advice or help from other people about what to do. *(Bendizama ukufumana incedo kwabanye abantu ngezinto endingazenzi.)*	1	2	3	4
E24.	I've been learning to live with it. *(Bendizama ukuphila nayo lemeko.)*	1	2	3	4
E25.	I've been thinking hard about what steps to take. *(Bendicinga uzulu ngezinyathelo ebendi ngazithatha.)*	1	2	3	4
E26.	I've been blaming myself for things that happened. *(Bendizisola mna ngendlela izinto zenzeka ngakhona.)*	1	2	3	4
E27.	I've been praying or meditating. *(Bendibandaza okanye ndicinge uzulu entliziweni yam.)*	1	2	3	4
E28.	I've been making fun of the situation. *(Bendihlekisa ngalomeko.)*	1	2	3	4

Notes:

F. DEPRESSION (CES-D)

Below is a list of ways that describe how you may have felt or behaved during the past week. Please tell me **how often** you have felt this way **during the past week**.
(Ngaphantsi kohlulidlu kwemibuzo yokufunaqa iindlela zokuba ucwise ngokuba uzivanjani okanye uziphethe njani ngexesha lale viki elidluleyo. Nceda undixelele ukuba kukangaphi uziva ujalo kwiviki elidluleyo.)

Circle one number on each line *(yenza isangqa kwinani kunugama adweliswayo)*:

0 = Rarely or none of the time (less than one day)
(mankqapha-nkqapha okanye zangendayenza lonto (ngaphantsi kokuphela kosuku)
1 = Some or a little of the time (1-2 days)
(intwan' encinci okanye ngamaxesha amancinane (1-2wezintsuku))
2 = Occasionally or a moderate amount of time (3-4 days)
(ngamanye amaxesha okanye maphakathi nendawo ngamany' amaxesha)
3 = Most or all of the time (5-7 days)
(kakhulu okanye'maxeshonke (5 kuya kwizintsuku ezingu7))

During the past week *(ngexesha leveki ephelileyo)*:

F1.	I was bothered by things that usually don't bother me. *(Bendikhathazwa zizinto ezingaqhelanga ukungandikhathazi.)*	0	1	2	3
F2.	I did not feel like eating; my appetite was poor. *(Andifunanga kwakudla, andaba nandla wokudla.)*	0	1	2	3
F3.	I felt that I could not shake off the blues even with help from my family or friends. *(Ndizive kwanzima ukungatyhafi noba bezama ekhaya nabahlobo bami ukundonwabisa.)*	0	1	2	3
F4.	I felt that I was just as good as other people. *(Ndizive ndilunge njengabanye abantu.)*	0	1	2	3
F5.	I had a problem keeping my mind in what I was doing. *(Ndibe negxaki yokunikela ingqondo yam kwinto endiyenzayo.)*	0	1	2	3
F6.	I felt depressed. *(Ndizive ndidakumbile.)*	0	1	2	3
F7.	I felt that everything I did was an effort. *(Ndive ndaziva yonke into endiyenzayo izinzame.)*	0	1	2	3
F8.	I felt hopeful about the future. *(Ndizive ndinethemba ngekamva.)*	0	1	2	3
F9.	I thought my life had been a failure. *(Ndicinge ukuba ubomi bam abuphumelelanga.)*	0	1	2	3
F10.	I felt fearful. *(Ndizive ndisoyika.)*	0	1	2	3
F11.	My sleep was restless. *(Ukulala bekungekho kuphumla nakuzola.)*	0	1	2	3
F12.	I was happy. *(Bendonwabile.)*	0	1	2	3
F13.	I talked less than usual. *(Ndehlise nokuthetha ngokwesiqhelo.)*	0	1	2	3

F14.	I felt lonely. *(Ndizive ndindodwa.)*	0	1	2	3
F15.	People were unfriendly. *(Abantu bebengenabuhlobo kum.)*	0	1	2	3
F16.	I enjoyed life. *(Ndibuvuyele ubomi.)*	0	1	2	3
F17.	I had crying spells. *(Ndibenento yoba ndivele ndilile.)*	0	1	2	3
F18.	I felt sad. *(Ndive ndizive lusizi.)*	0	1	2	3
F19.	I felt that people dislike me. *(Ndive ndizive ngathi abantu abangithiyileli.)*	0	1	2	3
F20.	I could not get "going". *(Ndingakwazi nakuqalisa no nyoni no.)*	0	1	2	3

Notes:

G. ANXIETY (SPIELBERGER STATE ANXIETY INVENTORY)

A number of statements which people have used to describe themselves are given below. Read each statement and then select the appropriate one to indicate **how you feel right now**, that is, at this moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.
(Zininzi iizindlela abantu abanokuzichaza ngayo, ezinye zazo zezi ezibhalwe ngezantsi. Funda ulubhu lwalengxelo, de wohlule evumelana nawe, ngendlela oziva ngayo, oku kukuthi, ngexesha langoku. Azikho iimpendulo ezilungileyo okanye ezingalunganga. Ungathathi ixesha elininzi kwintetho nganye kodwa sinike impendulo echaza ngendlela oziva ngayo okwangoku.)

Circle one number on each line *(yenza isangqa kwinani kwanga adweliswevo)*:

1 = Not at all *(hayi nakancinci)*
2 = Somewhat *(noko)*
3 = Moderately so *(ngokungagqithileyo)*
4 = Very much so *(kakhulu)*

G1.	I feel calm. *(Ndiziva ndizolile.)*	1	2	3	4
G2.	I feel secure. *(Ndiziva ndikhuselekile.)*	1	2	3	4
G3.	I am tense. *(Ndiziva ndixinzelelekile.)*	1	2	3	4
G4.	I am regretful. *(Ndiziva ndingamkelekanga.)*	1	2	3	4
G5.	I feel at ease. *(Ndiziva ndikululekile.)*	1	2	3	4
G6.	I feel upset. *(Ndiziva ndiphazamisekile.)*	1	2	3	4
G7.	I am presently worrying over possible misfortunes. *(Okwangoku ndiziva ndinexhala ngathi ndinamashwa.)*	1	2	3	4
G8.	I feel rested. *(Ndiziva ndingadiniwanga.)*	1	2	3	4
G9.	I feel anxious. *(Ndiziva ndixhalabile.)*	1	2	3	4
G10.	I feel comfortable. *(Ndiziva ndonwabile.)*	1	2	3	4
G11.	I feel self-confident. *(Ndiziva ndizithembile siqusani.)*	1	2	3	4
G12.	I feel nervous. *(Ndiziva ndiluphazamisekile.)*	1	2	3	4
G13.	I am jittery. *(Ndiziva ndintophakuphaku.)*	1	2	3	4
G14.	I feel "high strung". *(Ndiziva ndibuncwangu ngewangu.)*	1	2	3	4

G15.	I am relaxed. *(Ndiziva ndiphaanle.)*	1	2	3	4
G16.	I feel content. *(Ndiziva ndonelisekile.)*	1	2	3	4
G17.	I am worried. *(Ndiziva ndikhathazekile.)*	1	2	3	4
G18.	I feel overexcited. *(Ndiziva ndonwabe kakhulu.)*	1	2	3	4
G19.	I feel joyful. *(Ndiziva nchwayayo.)*	1	2	3	4
G20.	I feel pleasant. *(Ndiziva ndonwabile.)*	1	2	3	4

Notes:

II. SOCIAL SUPPORT (MOS SOCIAL SUPPORT SURVEY)

Next are some questions about the support that is available to you. *(Lemibuzo elandelayo yeyokufumana ukuba lohlobina uncedo olufumanayo.)*

H.1. About how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind)? Write in number of close friends and close relatives
Bangaphi abahlobo nezalamane zakho onaxo ovana nazo (abantu okhuhlekileyo ukuthetha nabo ngezinto ezisengqondweni yakho)? Bhala inani labahlobo nezalamane zakho

Please state who these people are and where they live. *(Nceda uchaze ukuba ngobani aba bantu kwaye bahlala phi na.)*

No.	Who *(ngubani)*			Place of residence *(Indawo yokuhlala)*
	First name *(igama lakho)*	Relationship to participant *(Ubudlelwane nomthathi nxaxheba)*	Line no. from household roster if applicable	1 = household *(umziwonke)* 2 = not in household, but in neighbourhood *(ahangekho kulomzi kodwa bengomelwane)* 3 = outside neighbourhood, but in Cape Town *(ahangaphandle komelwane kodwa behlala kwi dolophu laseKapa)* 4 = outside of Cape Town *(ngaphandle kwedolophu laseKapa)*
		Codes A		
H.1.1				1 2 3 4
H.1.2				1 2 3 4
H.1.3				1 2 3 4
H.1.4				1 2 3 4
H.1.5				1 2 3 4
H.1.6				1 2 3 4
H.1.7				1 2 3 4
H.1.8				1 2 3 4
H.1.9				1 2 3 4
H.1.10				1 2 3 4

People sometimes look to others for companionship, assistance, or other types of support. **How often** is each of the following kinds of support available to you if you need it? *(Ngamanye amaxesha abantu banokujonga kuhalingane babo, ukufumana uncediso okanye ezinye indlela zokuncedisana. Kukangakanani ufumana olunye lolunceda olufumanekayo kuwe xa uludinga?)*

Circle one number on each line *(yenza isingqa kwelinye lamanani adweliswayo):*

1 = None of the time *(alikho nalinye ixesha)*
2 = A little of the time *(ngexesha elincinci)*
3 = Some of the time *(ngamanye amaxesha)*
4 = Most of the time *(ngamaxesha amaninzi)*
5 = All of the time *(ngawowonke amaxesha)*

Now we'd like to know **whether or not you are satisfied** with the different kinds of support you receive. *(Ngoku sizakufuna ukwazi ukuba wanelisekile okanye hayi luncedo olwahlukeneyo olufumanayo.)*

1 = Happy with the support you receive (☺) *(wonwabile ngoncedo olufumanayo)*
0 = Not happy with the support you receive (☹) *(ulusizi ngoncedo olufumanayo)*

H.2	Someone to help you if you were confined to bed. *(Ukhona umntu onokukuncedela xa ugula ungasakwazi ukuzenzela nto ulele ebhedini.)*	1	2	3	4	5	1	0
H.3	Someone you can count on to listen to you when you need to talk. *(Ukhona umntu onokumamela xa ufuna ukuthetha maxesha wonke).*	1	2	3	4	5	1	0
H.4	Someone to give you good advice about a crisis. *(Ukhona umntu onokukucebisa ngokulungileyo xa usengxakini.)*	1	2	3	4	5	1	0
H.5	Someone to take you to the doctor if you needed it. *(Ukhona umntu onokusa kuggirha xa ndinga ncedo.)*	1	2	3	4	5	1	0
H.6	Someone who shows you love and affection. *(Ukhona umntu okunika uthando nobubele.)*	1	2	3	4	5	1	0
H.7	Someone to have a good time with. *(Ukhona umntu onokonwaba naye.)*	1	2	3	4	5	1	0
H.8	Someone to give you information to help you understand a situation. *(Ukhona umntu ongakunika inkcukacha ngoncedo lwakho.)*	1	2	3	4	5	1	0
H.9	Someone to confide in or talk to about yourself or your problems. *(Ukhona umntu onithembileyo ongathetha naye ngawe nangengxaki zakho.)*	1	2	3	4	5	1	0
H.10	Someone to hug you. *(Ukhona umntu onokwanga.)*	1	2	3	4	5	1	0
H.11	Someone to get together with for relaxation. *(Ukhona umntu ongahlala nave nonwabe kunye.)*	1	2	3	4	5	1	0
H.12	Someone to prepare your meals if you were unable to do it yourself. *(Ukhona umntu onokukuphekela xa ungakwazi ukuzenzela ngokwakho.)*	1	2	3	4	5	1	0
H.13	Someone whose advice you really want. *(Ukhona umntu onengcebiso ozifunayo.)*	1	2	3	4	5	1	0

H.14	Someone to do things with to help you get your mind off things. *(Ukhona umlingane wakho onokususa ingcinga zakho ezinzima nezikuphazamisayo.)*	1	2	3	4	5	1	0
H.15	Someone to help with daily chores if you were sick. *(Ukhona umntu onokukunceda ngemisebenzi yemihla yonke xa ngula.)*	1	2	3	4	5	1	0
H.16	Someone to share your most private worries and fears with. *(Ukhona umntu onokunxelela imbilini yakho okanye ukoyika.)*	1	2	3	4	5	1	0
H.17	Someone to turn to for suggestions about how to deal with a personal problem. *(Ukhona umntu ongakunamela xa udinga ingcebiso zokujongana nengxaki omelene nazo.)*	1	2	3	4	5	1	0
H.18	Someone to do something enjoyable with. *(Ukhona umntu onokonwaba naye.)*	1	2	3	4	5	1	0
H.19	Someone who understands your problems. *(Ukhona umntu oziqondayo ingxaki zakho.)*	1	2	3	4	5	1	0
H.20	Someone to love and make you feel wanted. *(Ukhona umntu okuthandayo nokwenza uthandeke.)*	1	2	3	4	5	1	0
H.21	Someone to help take care of your children when you can't. *(Ukhona umntu onokwazi ukukujongela abantwana bakho xa ungenakukwazi.)*	1	2	3	4	5	1	0

Notes:

GENERAL

Thank you for completing the interview. Before we finish, is there anything else you'd like to add which I haven't asked you about? *(Enkosi ngokugqiba udliwano-ndlebe. Phambi kukuba sigqibe, ingaba kukho into engeyenye onokuthanda ukuyongeza endingakhange ndikubuze yona?)*

Reminder:

(a) Return to page 1 and fill in the time completed and duration of the interview.
(b) Ensure that all codes and all line numbers from the household roster have been filled in where required.

CODES FOR COMPLETION OF QUESTIONNAIRE

For during administration (Codes C-F):

Codes C: Employment status *(imo ngomsebenzi)*

Additional codes:
DK = don't know *(andiyazi)*
NA = not applicable *(ayingeni)* [if < 7 years]

1. Paid employment** *(umsebenzi obhatalelwayo)*
2. Full time househusband / housewife *(mama / tata ohleli ekhaya)*
3. Going to school/college/university *(uhamba isikolo/ ikholeji/ idyunivesiti)*
4. Retired / pensioner *(umhlala phantsi)*
5. Not working, but wanting work and looking for it *(awuphangeli kodwa ufuna umsebenzi ukhangela wona)*
6. Not working, but wanting work and not looking for it *(awuphangeli kodwa uyawufuna umsebenzi awuwu khangeli)*
7. Not working and not wanting work *(awuphangeli awufuni msebenzi)*
8. Permanently unable to work *(ukungakwazi ukusebenza oko)*
9. Other (specify) *(enye, chaza)*

** For example, formal work for a salary, wage or profit; informal work such as making things for sale, selling things to provide a service; or casual work. *(Umzekelo, umsebenzi osisiqhelongemvuzo, inzala, umsebenzi ongamiselekanga ofana nokuthengisa ngamaxabiso aphantsi , ukuthengisa izinto unikeza uncedo, okanye umsebenzi ozenzekelayo.)*

Codes D: Type of grants *(uhlobo lwenkam-nkam)*

Additional codes:
DK = don't know *(andiyazi)*
NA = not applicable *(ayingeni)*

1. Old age pension *(yobudala)*
2. Disability grant *(yokukhubazeka)*
3. Child support grant *(yokonga umntwana)*
4. Care dependency grant *(yokukhathalela)*
5. Foster care grant *(yomntwana okhuliswa ngabanye abazali)*
6. Grant in aid *(inka-nkam yokunceda)*
7. Social relief *(yokumelana nentlalo)*

Codes E: Timing of care *(amaxhesha enkathalelo)*
[multiple responses possible]

1. Weekday mornings *(kusasa evekini)*
2. Weekday afternoons *(malanga evekini)*
3. Weekday evenings *(malanga evekini)*
4. Weekend days *(ngentsuku zempela veki)*
5. Weekend evenings *(ngempela veki malanga)*
6. All of the above *(konke okuphezulu)*
7. Other (specify) *(enye, chaza)*

Codes F: Types of care *(iiNtlobo yenkathalo enikwayo)*
[multiple responses possible]

1. Dressing and grooming *(ukunxiba nokuqeqesha)*
2. Feeding *(ukutyiswa)*
3. Transport to school or care facility *(ukuhanjiswa ukuya e crècheIsithuthi sokuya esikoleni okanye kwenye indawo yokungcinwa ngenkathalelo)*
4. Entertaining in or near household *(ukonwatyiswa ngaphakathi okanye kufuphi nomzi)*
5. Having child visit with him/her away from home *(ukutyelela nomntwana wakhe/naye kude nekhaya)*
6. Monitoring (not actively involved) *(ukumjonga (nje))*
7. All of the above *(konke okuphezulu)*
8. Other (specify) *(enye, chaza)*

For after administration (Codes A & B):

Codes A: Relationship to participant *(ubudlelwane nomthathi nxanxeba)*

1. Husband or partner* *(umyeni okanye iqabane)*
2. Son *(unyana)*
3. Daughter *(intombi)*
4. Father *(utata)*
5. Mother *(umama)*
6. Sister *(usisi)*
7. Brother *(ubhuti)*
8. Niece *(mtshana)*
9. Nephew *(mtshana)*
10. Aunt *(umakazi)*
11. Uncle *(umalume)*
12. Granddaughter *(mzukulwana wentombi)*
13. Grandson *(mzukulwana wonyana)*
14. Grandmother *(makhulu)*
15. Grandfather *(bawomkhulu)*
16. Mother-in-law *(mamazala)*
17. Father-in-law *(bawozala)*
18. Son-in-law *(umkhwenyana)*
19. Daughter-in-law *(nomdade)*
20. Brother-in-law *(ubhuti wase mzini)*
21. Sister-in-law *(indodakazi)*
22. Lodger *(umqeshi ndawo)*
23. Other family (specify) *(olunye usapho, chaza)*
24. Other non-family (specify) *(abangelo sapho, chaza)*

* A partner is defined as someone with whom the participant has an intimate relationship. *(Iqabane libhekiswa kumntu umthathi nxaxheba anobudlelwane obusondeleneyo.)*

Codes B: Education

1. None
2. Grade 0/R *(Ibanga 0/R)* [pre-primary]
3. Grade 1/Sub A *(Ibanga 1)*
4. Grade 2/Sub B *(Ibanga 2)*
5. Grade 3/Standard 1 *(Ibanga 3)*
6. Grade 4/Standard 2 *(Ibanga 4)*
7. Grade 5/Standard 3 *(Ibanga 5)*
8. Grade 6/Standard 4 *(Ibanga 6)*
9. Grade 7/Standard 5 *(Ibanga 7)*
10. Grade 8/Standard 6 *(Ibanga 8)*
11. Grade 9/Standard 7 *(Ibanga 9)*
12. Grade 10/Standard 8 *(Ibanga 10)*
13. Grade 11/Standard 9 *(Ibanga 11)*
14. Grade 12/Standard 10/Matric *(Ibanga 12)*

Additional codes:
DK = don't know *(andiyazi)*
NA = not applicable *(ayingeni)* [if < 7 years]

Appendix H. Interview transcript

CSSR Women Caregivers' Mental Health Project interview transcript:

Interview 3 with Zoleka – 01/02/2006

Zoleka: *Asizokuphuma ezireydweni?*[59]

Translator: *Hayi uzakubhala ireport yakhe* (She'll write her report). She wants to know if she won't hear her voice on the radio.

Interviewer: Oh!! No.

Zoleka: *Abanye abantu umntu anakujongela ukuba unento ethile.*
Translator: People might start talking about your status.
Zoleka: *Xa umntu ekuthuka akuthuke ngalonto ibe ingeyo ngxaki ongenayo ngulo ungekayo kuzitshekisha kuba wonke umntu unayo lento.*
Translator: No one can say they don't have it, everyone has got this thing, if you think you don't have it, it means you have not been tested.

Interviewer: Have you heard something like that before?
Translator: *Ukhe into enjalo before, eyokuba abantu bavele bakhutshwe ereydweni?*

Zoleka: *Hayi into kunayo ndiyazicingela.*
Translator: No, I was just thinking.

Interviewer: No, I promise you, you will never hear your voice on the radio or see your face on TV.
Translator: *Siyakuthembisa awuzokuvakala reydweni okanye thivini, yonke lento ithethwa apha izakusetyenziselwa for iresearch.*

Zoleka: Ok.

Interviewer: And also when we talk abaout the things you say we never use your name. No one will be able to find out that it was you who said those things.
Translator: *Naxa sisebenzisa lento usixelele yona asisebenzisi gama lakho. Akukho mntu azakuyazi ukuba nguwe obuthethe lento.*

Zoleka: Ok.

[59] In order to improve the readability of the transcript for non-Xhosa speakers, all isiXhosa text has been italicised. Further, English text that has been translated into isi-Xhosa or vice versa, or sections of conversation where translation was provided intermittently, are grouped together.

Interviewer: So if there is something that you say, that we've spoken to you about together with these two other women who live in this area, so we put everything that you all say together.
Translator: *Lento usixelele yona idityaniswa nezinto esizixelelwe ngabanye abantu esithe sasthetha nabo, ibhalwe yonke kunga bhalwa magama abantu.*

Zoleka: Oh-ok.

Interviewer: Ok. How are you?
Translator: *Unjani?*

Zoleka: *Ndiphilile. Unjani wena? Andazinokuba uyabuzwa na.*
Translator: I am ok. How are you? (I'm not sure if I should ask)

Interviewer: I'm well, not so bad, it's just hot today.
Translator: *Uthi uphilile naye qha kushushu namhlanje.*

Interviewer: Were you working at your stall before you came here?
Translator: *Ubusebenza estandini sakho before uze apha?*

Zoleka: *Hayi bendingasebenzi senditshonile ngoku.*
Translator: No she no longer has the store, she went bankrupt.

Interviewer: Oh! What happened?
Translator: *Kwenzeke ntoni?*

Zoleka: *Hayi ndizaqala ngokutsha ngoku ditshoniswe ngabantu balapha abathengi izinto zonakale, izinto ezinjengee tomata, iiapile, amatswele, iikhaphetshu ziyonakala. Abafuni kuthenga.*
Translator: It's the people, they don't buy. Things end up getting rotten because people don't want to buy. Things like tomatoes, apples, onions and cabagges get rotten very quick. So I will start all over again.

Interviewer: Was it quiet over Christmas?
Translator: *Bekuthe cwaka ngelixesha le Christmas abantu zange bathenge?*

Zoleka: *Ewe khange bathenge, ndatshona kengoku.*
Translator: It was very quiet, hence I went bankrupt.

Interviewer: Hmm. Things seemed to be going so well the last time I saw you.
Translator: Ubuqhuba kakuhle nje ukugqibelana kwethu.

Zoleka: *Ewe bendiqhuba kakuhle kodwa ke kulo nyaka ndifuna ukuqala enye into. Ndifuna ukuthengisa idrinki ngoku yona nto ingonakaliyo.*
Translator: Yes, I did very well, but this year I want to start something else like cooldrinks. Something that does not go off.

Interviewer: Especially when it's so hot.
Translator: *Ingakumbi xa kushushu kangaka.*

Zoleka: *Ewe, nee zinto ezinjenge swekile, iimealie-meal, zonanto zingazokonakala.*
Translator: Things like sugar, maize-meal don't go off..... (Zoleka: *nefish oil*) and cooking oil.

Interviewer: You sound like a lady who's always got a plan.
Translator: *Ubonakala njengomntu osoloko enecebo.*

Zoleka: *Ewe andifuni kuzihlalela nje ndifuna ukuzama. Ndikwazi ukuthi lemali ndiyifumanayo ndiyibeke ndingadlaleli kuyo. Into endingenayo ndimana ukuthatha kulaa mali.*
Translator: Yes, I don't want to just sit and do nothing. I want to be able to save my grant money. So I want to do something to add on to what I'm getting.

Interviewer: You are still getting your grant, hey?
Translator: *Usayifumana igrant?*

Zoleka: Ewe.
Translator: Yes.

Interviewer: How long has it been now, four months?
Translator: *Zinyanga ziyi four ngoku uyifumana?*

Interviewer: And how do you manage - getting your grant without getting any extra money? Do you manage? Do you manage to live on your grant?
Translator: *Uyakwazi ukuziphilisa, njengokuba ngoku ungasasebenzi nje ufumana igrant yodwa. I yazenela iingxaki zakho?*

Zoleka: *Isazonela iingxaki zam but ndiye ndafaka umntana esikolweni loebeyekile, wamitha, lomntanana umncinci ubelekwe ngulona, ndamphindisa esikolweni. Ndiyawufuna ke nomsebenzi ndizisebenzele.*
Translator: It does cover most of my problems for now, but I don't know because I have sent my daughter back to school. The one who fell pregnant, I have sent her back to school. I need to look for a job now.

Interviewer: This is your younger daughter?
Translator: *Ngulo mntana umncinci?*

Zoleka: *Ewe, ngulo una 13.*
Translator: Yes, it's the 13-year-old.

Interviewer: And how does she feel about going back to school?
Translator: *Uziva njani ebuyele esikolweni?*

Zoleka: *Hayi uvuyile kakhulu xa ebuyela esikolweni. Ayingomntu usonqenayo isikolo uyasithanda isikolo. Ebehlupheka nangoku ebehleli nje qha ndathi makakhe ahlale akhulise nje umntana, umshiye apha kum kengoku.*
Translator: She was very glad because she is a bright kid and she likes school very much. She actually got sad when she couldn't go back to school because she had to care for the baby.

Interviewer: Is she at the school close by?
Translator: *Ufunda apha kufutshane?*

Zoleka: *Ufunda eKraaifontein.*
Translator: In Kraaifontein.

Interviewer: And is she travelling there everyday?
Translator: *Uyakhwela ukuya pha, ubuya qho?*

Zoleka: *Uhlala kwabhutana wakhe uyabuya ngee weekends, ngezinye iiweekends angabuyi. Ngezinye abuye.*
Translator: No she lives in Kraaifontein *[Nobhuti wakhe? (Zoleka: Ewe ngumntana wodade wethu qha mdala)]* with her cousin who is older than her, he's a young man. Then she comes home on some weekends.

Interviewer: Is this the cousin you stayed with when you moved from Jo'burg?
Translator: *Ngulo wawuhlala naye ngokuya wawubuya eRhawtini ubhutana lo?*

Zoleka: Ewe.

Interviewer: This will give you a chance to see your friends in Kraaifontein more often?
Translator: *Lento izakupha ithuba loba ubone izihlobo zakho zase Kraaifontein qho kengoku kuba umntana ehlala pha?*

Zoleka: *Ewe izakundenza ukuba ndibone izihlobo zela cala. Enye into kengoku sendifuna nokuphindela ngaphaya, ndibenendlu ekwelacala. Ikhona landlu yayindixoxisa phantsi koggirha walandoda ndandihlala nayo. Ngokuke bayandifuna ukuba ndizokuyijika kuba abangeni ndawo kubs bayijike bona.*
Translator: Yes it will give me an opportunity to reconnect with my friends that side. I'm also planning to move to that side because the house I once stayed in with my husband, there were some problems with it, they have called me now to say they have sorted out the problems, I can go stay there.

Interviewer: So instead of going back to Jo'burg, you want to go stay in Kraaifontein?
Translator: *Endaweni yoba ngoku ubuyele eRhawtini ucinga ukuya eKraaifontein?*

Zoleka: *Ewe ndicinga ukuba mandiye eKraaifontein kuba waphelelwa umntakwethu lo bendizakuya kuye pha ngumsebenzi.*
Translator: I was thinking of going back to Kraaifontein because my brother in Jo'burg is unemployed.

Interviewer: Were you happy when you were living there before?
Translator: *Kwakumnandi eKraaifontein wawonwabile?*

Zoleka: *Kwakumnandi kuba bendibhizinisa pha ibusiness yam ihappy.*
Translator: I was very happy, my business was booming.

Interviewer: What kind of business did you have when you were living in Kraaifontein?
Translator: *Ubune business enjani ngokuya ubuhlala pha?*

Zoleka: *Bendithengisa inkuku, ndixhwitha inkuku, ndithengisa imielie-mielie, ndithengisa ifish oil, mandithi yonke into yevenkile ibisi spaza.*

Translator: I had a spaza shop, I was selling live chickens, I sold everything, maize meal, cooking oil, everything that you will find in a spaza shop *(Zoleka: ne drinki)* cool drinks as well.

Interviewer: And, and business was much better there than it is in Crossroads?

Translator: *Yayibhetere ibusiness pha yayihamba noko kunalapha eCrossroads.*

Zoleka: *Ewe babengandisokolisi ndandisithi apha ezinkukwini bathathe ngoLwesihlanu bazokubhatala ongezanga uzokubhatala azokuxelela ukuba ndizakubhatala ngeveki ethile.*

Translator: The people there supported my business, as I was selling live chickens, they would come during the week to take on credit and on Friday they would come and pay and if they don't have money they will still come, explain the situation and pay me the following week.

Interviewer: You mentioned there were some problems after your husband's death, you were not sure if you could go back but now you think it's alright. Can you tell me a bit more about that?

Translator: *Ubukhe wathi bekukho iingxakana ukuze umnke kulandlu eKraaifontein.....*

Zoleka: *Oh, kwathi kwakusweleka landoda bendihlala nayo abantu bakowabo bafuna ukuthatha lampahla ipha phakathi, babefuna ukundihlaba ke.*

Translator: Oh, when the man that I was staying with died, his family wanted to take everything that was in the house and it was this whole fight, they wanted to stab me.

Zoleka: *Ababango brother bakkhe ngabo abababenengxaki, aba bangaba ntakwabo bengena ngxaki bandikhululela yonke into esendlini (Translator: Ngobani ababenengxaki?) ngaba bangodade wabo.*

Translator: His sisters were the ones with issues. His brothers were actually fine with me staying in that house.

Interviewer: Do you think, they thought you had something to do with their brother's death?

Translator: *Ucinga ukuba babe kurhanela ukuba unentokwenza nokusweleka kobhuti wabo?*

Zoleka: *Hayi into ababeyifuna zii fridge kuba washiya iifridge ezimbini. Kunye nempahla, yayiseyitshile enye impahla. Befuna na landlu kuba izakwakhiwa ibesisitena.*

Translator: No, what they actually wanted was the furniture that was inside especially the two refrigerators. The other thing was the house because the government was about to build brick houses.

Interviewer: So they got just about everything and you had to leave with nothing?

Translator: *So bazifumana zonke izinto, wena wahamba ungenanto?*

Zoleka: *Ewe babefuna ndihambe ndingena niks qha kemna ndayithutha lampahla ngobusuku, ndayithuthela ngapha enye, enye ikwelacala. Nabantakwabo babe besithi mandihlale phaya akhonto ndizakuyenziwa babe bendileqa aba ababangabatshana baphaya bangamadyongwanyana.*

Translator: They actually wanted me to leave with nothing, but I took everything overnight without them seeing. His brothers wanted me to stay, but their nephews were actually chasing me out.

Zoleka: *Babengamhoyanga, umthetho walamntu ebenokugula kwentloko le qha ke ibinenyanga yayo lento, abhadle ebengumntu ebebhadlile qha ifika ngaloo nyanga ashiywe zingqondo bangafuni xa ephambeneyo ba maka ngene ezindlini zabo.Ndamhlalela kemna ndahlala naye emveni koba eswelekile kengoku bafuna ezanto zinga phakathi bebe ngamhoyanga bona.*

Translator: They didn't care about him when he was still alive. He had a mental problem that often came at certain times in the year. So I took care of him. I tolerated all that and made sure he was well looked after. When he was dead they demanded everything, while they wanted nothing to do with him when his was still alive.

Interviewer: You said he had a mental illness. What happened to him when he was sick?

Translator: *Kwakusenzeka ntoni xa egula njengoba usithi wayegula ngengqondo nje?*

Zoleka: *Er...er... ebeye aphambane ngengqondo, enepilisi ke azityayo zale mpambano yakhe. Esola abantu ke, wayesithi ubulawa ke ngunina wakhe. Phakowabo kanye nodade wabo ubhubhe engabafuni oodade wabo.Ndadibana naye kemnake apha eKapa ndamamkela kuba ayingomntu obeligeza, qha ibimfikela nje lonto ngeloxesha. ndahlala naye. Ngoku ekuswelekeni kwakhe bafuna ezanto bezingaphakathi kodwa bayambaleka xa engaphilanga.*

Translator: No, he'll just go crazy but he had medication for that. But that was not regular it would come at a certain time in the year. He kept saying he was being bewitched by his mother. His sisters ran away from him. So she met him when she got here in Cape Town and accepted his condition 'cause it would only once in a while. So she does not understand why now they were demanding everything because they wanted nothing to do with him.

Zoleka: *Nasesibhedlele wayesiwe ndim. Ndanantsika ndamsa ngoLwesine, ndabe ndayokumkroba ngoLwesihlanu ndafika kusithiwa uswelekile. Emveni koko ke ngoku ndabaxelela abantu bakowabo. Basuka bafuna lempahla ingaphakathi odade wabo, ababangabantakwabo bathi abanofika seberhwaphiliza oodade wabo bezokufuna ilifa bebe ngamhoyanga.*

Translator: I'm the one who took him to the hospital, it was on a Thursday and he died on the following day. I went to tell his family. It's then that his sisters started to make their demands and his brothers said they cannot inherit anything because they did not care about him.

Interviewer: It sounds like it was a horrible time for you?

Translator: *Ingathi ibilixesha elibi kakhulu for wena eliya?*

Zoleka: *Ewe yayilixesha elibi, mna ndabuya nalonto uba uswelekile bebengamhoyanga, xandifika pha mortuary kwathiwa ubenesisigulo esi*

silapha kum kengoku na, wabe engazange andixelele ukuba unayo lant'ithile ndava sendi pha ukuba kunyuke yona waza wasweleka.

Translator: It was very bad, especially having to tell his family bcause they did not care. When I went to the mortuary, I was told that he had this illness that I've got now, but he never told me that he had this. So they told me that it affected him mentally that's how he died.

Zoleka: *Wabe engasebenzisi ke napilisi zalanto*

Translator: He never used any medication.

Zoleka: *Wayendifihlela ke ukuba unalanto kuba nam ndiyifumene kuye ke, bendingayazi nam ndiyifumene pha emortuary.*

Translator: He kept it a secret and I got it from him, the first time I heard about it was in the mortuary.

Zoleka: *Ngoba ibingumntu obenabantu abaninzi, amankazana wakhe emaninzi intombi zakhe, endibona ukuba wayifumana apho kengoku.*

Translator: He was quite a lady's man so I suspect he got it from sleeping around.

Zoleka: *Ndabe ndijonge kemnake inoba yiTB, ndanditshekishise iTB eclinic, kwabe kuthiwa yiTB, esebenzisa ezapilisi zam.*

Translator: He used her TB medication because she was diagnosed with TB from the clinic so they shared medication.

Interviewer: It sounds to me like you must be quite a strong woman to keep going despite the difficult things you've been through. Is that how you see yourself?

Translator: *Ubonakala ngathi ungumntu ostrongo kakhulu ukwazi ukunyamezela izinto ezibuhlungu kangaka ezikwehleleyo uqhube ke uphila, ingaba nawe uzibona ngolohlabo, njengomntu ostrongo?*

Zoleka: *Ewe ndiyafuna ukuzenzela izinto zam ndingaxhomekeki.*

Translator: Yes, I want to do my own thing, I don't want to rely on other peple.

Zoleka: *Ngoba naye ndandidibane naye ndizisebenzela, ndingahlalanga phantsi.*

Translator: Because when I met him I was working. He didn't find me doing nothing.

Interviewer: It must have been difficult for you when you had to move to Crossroads, living with your cousin, not earning any money [Recording unclear] difficult for an independent woman to be in that kind of a situation.

Translator: *Inoba kwakunzima kuwe ukuza kwakho apha eCrossroads, ungaphangeli, kungekho mali uyifumanayo uhlala nocousin wakho.....*

Zoleka: *Kwakunzima ukuza kwam apha. Ndandikwazi ukulala ndingatyanga iintsuku zibentathu, ndabe ndingasebenzi ke ndihlala kwelicala komnye wefamily wapha kuthi wandithatha ndeza ngapha. Ukubeni endithathile kengoku ndahlala engakwazi ukubana asinike ukutya, sihlala sinjalo. Ithi izesifumane ukutya, ndizokuncedakala apha nalomntana lo ndimphindise esikolweni.*

Translator: It was very difficult moving to this side. We would spend something like three days without food. I didn't have a job, I stayed with a relative. The

only time where we would get food would be when I come to the clinic for food parcels. It was difficult because I had children as well.

Interviewer: Children and grandchildren.
Translator: *Nabazukulwana, ukubanabantwana nabazukulwana kwenza kwaba nzima kakhulu.*

Zoleka: *Abantwana babe nantsika, lo umncinci ndambona apho ukuba ukhulelwe ngoske alunywe ukuba isisu sasingabonakali. Lo umdala unyuke ngozokubelekela keyena usandukufika (Translator: Wawuhlala nalo umncinci) ewe.*
Translator: It's only the younger one who was here. The older daughter joined us later on. That's when I discovered that the younger daughter is pregnant.

Interviewer: The first time we met with you, you explained the way you live in your house, that you live with your cousin and his girlfriend and they don't share either money or food with you. I was trying to visualise for myself what that's like.
Translator: *Ngokuya wawuthethe nabo kuqala nhe wawuthe uhlala no cousin wakho ne girlfriend yakhe, and abaniphi kutya kodwa abaniphi kutya, so inoba injani imeko enjalo nihlale nonke, bayatya bona nina anityi?*
Interviewer: It sounded almost like, even though ... [Zoleka interrupts]

Zoleka: *Mandithi ebengenamsebenzi ulantuka, lo wasekhaya ebengenamsebenzi ubhadlileyo, ngoba xa kunetha ebeye ahlale angaphangeli xandiye ndayokuyifuna imali kwelacala andinike noba yi R60.00. Abandikubo apha andizalani nabo qha ngabe lali efamilini. (Translator: aba uhlala nabo ngoku). Uhm.*
Translator: The person.... the peope that she stays with now are not her relatives, they are people that she knows back from home. But the relatives are actually helpful, if they have something they do give her, even if it's R60.00. It just that they don't have a steady job.

Interviewer: These people that you were staying with, you were really living separate lives. You and your daughters were doing your own thing, separate from them?
Translator: *Ababantu ubuhlala nabo bebeziphilela ubomi babo bona bezityela ukutya kwabo, nawe nee ntombi zakho nizenzela ezenu izinto.*

Zoleka: *Ewe ngozicela apha eclinic, siye siphiwe apha eclinic. Okanye siye ngapha eMitchelsplein emaqheyeni siyokucela khona. siye sifumane ngaphaya sibuye sitye babe besebenza bona bezityela bodwa endlini kodwa sihleli sonke apha endlini.*
Translator: Yes, they were doing their own thing and we would get food from the clinic or go to Mitchellsplain, to the coloured community and beg for food. They had jobs and they would eat in front of us without sharing or anyhing like that.

Interviewer: Was it a couple, man and a woman, that you were staying with?

Translator: *Ngabantu ababini, yindoda nomfazi...?*

Zoleka: *Ewe ngumntu nentombi yakhe, abatshatanga qha uyahlalisana, uthatha lo athathe lo.Ngoku ingqondo, ingulo ufika neyakhe ingqondo lomntana, nomnye afike neyakhe ngokunjalo.*
Translator: Yes it's a man and a woman but this guy keeps changing women, so each one of them brings their own mind.

Interviewer: You said you know this person from back home?
Translator: *Lomntu sisihlobo sakho osaziyo kwasemva ekhaya?*

Zoleka: *Ewe siselalini enye qha isiduko sethu siyi one.*
Translator: Yes, they are in the same village and there is some relationship between their families.

Interviewer: Is it a clan relationship?
Translator: Yes.

Interviewer: Tell me what kind of work does he does? I remember you said he does have an income.
Translator: *Usebenza phi? Wawuthe unayo imali ayifumanayo.*

Zoleka: *Usebenza econtractini qha andiyazi ukuba usebenza ndawonina kodwa yi contracti.*
Translator: He works does construction work, building.

Interviewer: Do you know how far he went with school?
Translator: *Awumazi ufunde kangakanani?*

Zoleka: *Ukufunda (Translator: Uhm) akanaskolo uyafana nje nam ba ndihlela pha nje.*
Translator: He's never been to school, he's just like me he does not have any education.

Interviewer: Speaking about education, what does you oldest daughter think of her sister going back to school?
Translator: *Ucinga ntoni umntana wakho lo umdala xa usister wakhe esiya esikolweni?*

Zoleka: *Wathi akafuni kufunda yena, undohlule ke nam.*
Translator: She said she does not want to go back to school. I've given up now.

Interviewer: Do you think she cares at all that her sister is going back to school?
Translator: *Ucinga ukuba u.....imenza umnqweno intoyokuba usister wakhe ebuyela esikolweni.*

Zoleka: *Uske athi uyakufunda emaxhoseni, andimazi.*
Translator: She just says she will go back and go to school in the Eastern Cape.

Interviewer: Do you think she can do that?
Translator: *Ucinga ukuba uzakuyenza lonto wena?*

Zoleka: *Akazukuyenzakuba nangoku ndandimshiye phaya ndandimthengele yonke into ne uniform wahlala phantsi akafunda. Ndabe ndilapha.*
Translator: I don't think she'll do that because I once left her there with everything, school uniform and all and she did not go back to school.

Interviewer: So you are happy at least you've got one daughter back at school?
Translator: *Iyakonwabisa xa kukho noko umntana omnye ofuna isikolo?*

Zoleka: *Ewe uyandonwabisa lo usifunayo isikolo kuba ndiye ndathenga yonke into, ndathenga i uniform, waphinda esikolweni. Ngokuke ndijongene nomntana wakhe ndityise yena kengoku, njengoba eyeke ibele.*
Translator: Yes, it makes me very happy. I even bought her school uniform and everything she needs for school. My only job now is to look after my grandchild, to feed him because he's no longer breastfeeding.

[Recording unclear]

Translator: *Unangaphi ngoku umzukulwana wakho akaka wugqibi unyaka?*

Zoleka: *Unonyaka onenyanga eziyifive.*
Translator: He's one year five months (Zoleka: *Nanku apha ngaphandle ngoku*) he's actually here, outside.

Interviewer: Last time you had the other grandchild?
Translator: *Wawuze nomnye umzukulwana ngokuya wawuzile kuqala?*

Zoleka: *Hayi yayikwanguye lo, lowa akafuni mntu, lona akafuni kushiyeka uhamba nam, lowa ke uthathwa ngu nina akandifuni nam.*
Translator: No it's actually this one (Interviewer: the same) Yes, the other one does not want anyone except the mother (Translator to Zoleka: *uqhele ukubelekwa ngunina akamfuni omnye umntu*) She's used to be with the mother all the time.

Interviewer: How will you manage to work and look after the child as well?
Translator: *Uzakukwazi njani kengoku ukusebenza uphinde ugcine umntana?*

Zoleka: *Ndingakwazi ukusebenza kuba lona ukhoyo akanangxaki, lona umntana ukhoyo, ningakwazi ukusebenza. Yena akajonganga nina uyahlala noba ukubani.*
Translator: She could actually manage to work because her grandchild is not a problamatic child. You could just leave him with anyone.

Interviewer: I remember when you brought him during our last interview he was quiet. He did not interrupt at all.
Translator: *Ngokuya wawuzile naye yayingumntana oright akakhali zange enze nangxolo.*

Zoleka: *Hayi qha uba umtyisile yena uyalala akanayo kwanto.*
Translator: He does not have a problem at all, if you just give him food he just sleeps.

Interviewer: Do you see it as a challenge that you have to juggle work and a baby to look after or it's something that ... it comes quite easy to you?
Translator: *Ingaba izisa ubunzima into yokuba uzakube usebenza ngapha kwelinye icala kukho umntana ekufuneka umjongile, ingaba yinto oyiqhelileyo so awuboni ukuba ingayingxaki?*

Zoleka: *Hayi akunakubakho ngxaki ngoba ke ndizakusebenza ndimane ndibuya late, ukuba ke ndiyawufumana ndimana ndibuya late.*
Translator: No, I don't see it as a challenge because I will go to work and come back in the afternoon.

Zoleka: *Lo ungafuni skololo umdala abe ethingisa apha endlini kuba ndinayo ifridge yam.*
Translator: My older daughter would be selling in the mean time because I've got a fridge at home.

Interviewer: So the plan is to share child care and work with your older daughter?
Translator: *Ingaba injongo zakho kukuba lomntana wakho umdala akuncedise ekugcineni abantwana wena ukhabe usebenza?*

Zoleka: *Ewe xa engafuni kufunda makandigcinele umntanalona ndibe ndisebenza xandiwufumanayo mna?*
Translator: If she does not want to go to school its better that she take on child care responsibilities while I'm busy working.
Zoleka: *Ngoba kwalamali ayikho leya yale grant.*
Translator: Becuse we can't live on a grant, it's too little.

Interviewer: So she will look after these two children so that you can be able to go to work?
Translator: *So uzakubagcina bobabini abantwana ukuze ukwazi ukuya emsebenzini?*

Zoleka: *Ukhona lomntana lo ufikayo, ndibone kumi ibhasi ngomgqibelo, ngokadade wethu, ungakanana (making hand gestures) naye bendithe xa bendizama ukuthi ndizakumfaka esikolweni akana report uthi yalahleka emaxhoseni. Usenokuhlala nalomntana.*
Translator: There is this other child we saw arriving on Saturday, from the Transkei, she is my niece. She is about this height (making hand gestures) I tried to get her to go to school but she lost her school report in the Transkei. So she can look after my grandchild.

Interviewer: How old is she?
Translator: *Unangaphi iminyaka?*

Zoleka: *Una 15.*
Translator: She's 15.

Interviewer: Do you think she is old enough to be able to help you?
Translator: *Ingaba umdala ngokwaneleyo uzakukwazi ukunceda* (Zoleka: *andiva ke?*) *Umdala ngokwaneleyo ukuba angakwazi ukunceda?*

Zoleka: *Ja, angakwazi ukubeleka umntana, uyakwazi ukumtyisa.*
Translator: Yes, I think she will be able to look after the child.

Interviewer: Was she sent here to go to school?
Translator: *Ebethunyelwe apha ukuba makazokufunda?*

Zoleka: *Hayi usuke wazimela wenyuka waza apha, ndabona ibhasi sele imile kemnake ndabhatala loobhasi.*
Translator: She ran away from home; nobody knew she was coming. I was even forced to pay for her busfare.

Interviewer: Now suddenly you've got one more person to look after?
Translator: *Ngoku kukho nomnye umntu owongezelelekileyo ozakuxhomekeka kuwe?*

Zoleka: *Ewe, ukhona.*
Translator: Yes, there is.

Interviewer: And there is no one else back home that may help to pay for her food and everything else?
Translator: *And akekho omnye umntu ekhaya emaxhoseni onokunceda akuthumele imali abhatalele yena ukutya neziye izinto.*

Zoleka: *Utata wasweleka umntu okhoyo ngumama ngoku bendimeliba ndincedisane naye emaxhoseni ngobake akanamntu mdala. (Translator: Akakho onokunceda ngoku for lo ulapha umntana akuthumele imali) Ha-aha.*
Translator: There is no one. At first she said her father passed away, there is only her mother who's also in need of her support.

Interviewer: So who did she live with?
Translator: *Ebehlala nabani umtshana wakho?*

Zoleka: *Ebehlala no mama wam nomnye udade wabo omdala nyana oyintanga nalo wam umdala.*
Translator: She was with her sister and Nomphumelelo's mother.

Interviewer: So they know now she's come down here she is with you?
Translator: *Bayamazi uba ulapha ngoku (Zoleka: ewe) ububaxelele?*

Zoleka: *Ewe, bayamazi.*
Translator: Yes.

Interviewer: I wanted to ask earlier, do you still have your daughter's old report card when she needs to go back to school?
Translator: *Umntana wakho lo umdala usenayo ireport yakhe ukuba angafuna ukubuyela esikolweni?*

Zoleka: *Akanayo, wayilahla.*
Translator: She doesn't have, she lost it.

Interviewer: And does that cause a problem at all?
Translator: *Ingayingxaki lonto mhlawumbi?*

Zoleka: *Lo umdala akasifuni nokusibona. Ingabayingxaki kuba apha kwezizikolo kuzakufunwa ireport.*
Translator: It could be a problem because all the schools around here demand a report, but my daughter does not like school at all.

Interviewer: Was it a problem for your daughter in Kraaifontein now?
Translator: *Ibiyingxaki kulomntana wakho ufunda eKraaifontein?*

Zoleka: *Ewe ibiyingxaki kulo ungaphaya bendifuna ukumfaka ngapha intokunayo yabe iireport zakhe zalahleka ezintathu. Bazilahla ngelaxesha sasi gquduza sisizangapha.*
Translator: Yes it was problem to get a school this side because we lost all her three reports when we were moving this side, given everything that was happening at that time.

Zoleka: *Kwathiwa kengoku makabuyele eKraaifontein kuba ingekho ireport.*
Translator: She had to go back to Kraaifontein because she did not have a report.

Interviewer: But at the school in Kraaifontein they were okay?
Translator: *EKraaifontein babe right bona ba makangene esikolweni zange bamsokolise?*

Zoleka: *Hayi zange bamsokolise.*
Translator: No, they did not give her any problems.

Interviewer: In what standard did they make your daughter go to?
Translator: *Bamngenisaku grade bani bona?*

Zoleka: *Usangena ku 4.*
Translator: She's in standard 4.

Interviewer: And what standard was she in the last time she was at school?
Translator: *Ugqibelisa kwakhe esikolweni ebefunda bani?*

Zoleka: *Ebeyeke ku 4 phakathi wamitha lomntana.*
Translator: She was in standard 4 when she fell pregnant.

Interviewer: And how is she managing with her school work?
Translator: *Unjani kengoku nomsebenzi, umphethe njani umsebenzi wesikolo?*

Zoleka: *Hayi usicacelwe kakhulu isikolo, ndithi noba ndithi makangayi hlawumbi ngelaxesha ebe ngekabikho omnye lona akafuni ukungayi esikolweni.*
Translator: No, she likes school very much. She does not even want to miss a day.
Zoleka: *Akafuni ukuphoswa kuthiwe akayanga.*
Translator: She would not miss a day of school.

Interviewer: It's wonderful [Recording unclear]
Translator: *Yinto entle leyo...*

Zoleka: *Hayi ndiyayithanda ebelele apha ngoLwesihlanu, ndithe ndisithi hayi uyakuya ngomso, wathi akanakwazi angafika agxothwe, ndayokumkhwelisa eterminus.*
Translator: She actually slept over the other day and I told her not to go to school the following morning and she refused so I had to take her to the terminus.
Zoleka: *Uclever yena umoshwe ku mitha zange khe kuthiwe eleke nyaka ufelishile qho uyapasa.*
Translator: She's actually a clever kid. This pregnancy disturbed her schooling. She's never failed a single standard, she passes every year.

Interviewer: Were you surprised when she fell pregnant?
Translator: *Wothuka ukumitha kwakhe?*

Zoleka: *Ndabona selebeleka kaloku uthi wayengazazi ukuba umithi, nam ndabona sele elunywa umntu ezakubeleka isisu asikho tu seleza kubaleka qha.*
Translator: We actually discovered when she went into labour that she was pregnant. There no signs at all, the stomach was not showing, so we did not know.
Zoleka: *Kwathiwa makaqhaqhwe kuba unyukwe yi high blood ba lanto uyicinga yedwa, ba ndiyaqonda ukuba wayezazi qhaeyicinga yedwa.Kwathiwa xa inongakhutshwa lanto kukufa kwakhe, ndasayina ukuba makakhutshwe lamntana.*
Translator: She had to get a ceasarian section because she had problems with high blood pressure. We suspect that she knew, but she couldn't tell anyone that's why she had high blood pressure...
Zoleka: *Ndambona emana efainter, emane efainter, ndathi ndisokumsa eclinic kule ipha ezantsi kwathiwa ukhulelwe.*
Translator: She kept collapsing and they took her to the clinic and they said no she is pregnant.

Interviewer: It must have been a big shock for you find out so late.
Translator: *Inoba wothuka kakhulu, ukuva ngoku selezakubeleka ukuba umntana wakho umithi.*

Zoleka: *Ndothuka, ndothuka nyhani, xakusithiwa zoyisakele ezalapha iclinic waqhutyelwa eGrooteschuur, wayobelekela khona, wasikwa ke.*
Translator: It was a big shock indeed. The clinics around here said it was beyond their control so she was taken to Groote Schuur where she was operated.

Interviewer: Despite everything you have two lovely healthy grandchildren that you are very fond of.
Translator: *Emvakwayo yonke lento yenzekileyo kubonakala ngathi uyavuya nhe, unabazukulwana ababini abaphililileyo obathandayo.*

Zoleka: *Ewe ndiyavuya ba zange ndibenabantwana babababayi two qha, ndiyavuya nalo sele khona qha mandondle qha ba bazelwe abantwana abazokuthwani.*

Translator: Yes, it is exciting because I never had like a lot of children I only managed to have two and now that the house is full I must just work hard to feed them. What else can I do?

Interviewer: I wanted to aks you a bit about how are you doing. We've been talking about everybody else now, how are you doing? How has your health been?
Translator: *Silibele kukuthetha ngabanye abantu sidesalibala nokubuza ukuba eyakho impilo injani?*

Zoleka: *Hayi andiva kwanto mna, ndiziphilele nje oko yayivele indim ndivela nje.Qha ingxaki ebendinayo yeyoba ndibenelihlo eliye laqaqamba. Ndaya eclinic ndalifumana iyeza lamehlo.*
Translator: I'm actually very healthy, I haven't had anything wrong. It was just my eye that got so painful I came to the clinic and they gave me eye drops.
Zoleka: *Andiva nto kuba ndandiya ndidumbe inyawo ndinephika azisa dumbi nee nyawo zam.*
Translator: I'm feeling good now, my feet used to swell and I used to have breathing problems, but now I'm fine.

Interviewer: When did you have problems with your feet and your breathing?
Translator: *Ubunalo nini iphika nokudumba kwenyawo?*

Zoleka: *Ndandinalo ngelaxesha ndandingekafumani ezipilisi ezindizisebenzisayo.*
Translator: It was before I started on the medication.

Interviewer: What happened to your eye that you came to the clinic for?
Translator: *Bekusenzeka ntoni emehlweni akho ukuze uze apha eclinic?*

Zoleka: *Ebesuka abebomvu nje lingaqaqambi, kuba nangoku libomvu kodwa alibuhlungwanga.*
Translator: They just turn red (Interviewer: Blood shot?) yes (Zoleka: *abengathi ayarhawuzela qha*) but there is no pain, they just become itchy.

Interviewer: How long were you feeling like that for?
Translator: *Lixesha elingakanani ubuziva unjalo, unalento?*

Zoleka: *Ndineveki.*
Translator: It's been a week.

Interviewer: They actually gave you something; are you feeling fine now?
Translator: *Bakunika iyeza, lakunceda phofu?*

Zoleka: *Ewe landinceda, qha belili ncinci ndizakuphinda ndize nangoku.Ngoba idate yam ingoLwesithathu kule veki le izayo.*
Translator: Yes, I got something and it helped. I need to come again because it's finished now and my appointment is next week Wednesday.

Interviewer: And you are due for your sixth month visit now?
Translator: *Uzakuza for inyanga yesithandathu ngoku xa usiza apha eclinic?*

Zoleka: *Ewe, izakube iyinyanga yesithandathu ndizisebenzisa ezipilisi.*
Translator: Yes, it will be my sixth month on this medication.

Interviewer: When we first interviewed you, you had just started your treatment.You said that you were feeling a little bit better. If you think back now, before you started the treatment, have you continued to feel better as the time went on?
Translator: *Xa ujonga kwezinyanga zintandathu zidlulileyo. Wawuthe ukuqala kwakho ukusebenzisa amayeza waziva ubhetele kakhulu....*

Zoleka: *Ewe ndaziva ndibhetele kakhulu ukuqala kwam ukuzisebenzisa ndaziva ndinesiyezi iintsuku ezingaphi na ezimbini anda siva kengoku isizunguzane tot kude kubengoku.*
Translator: Yes, I felt much better after I had started. I had dizzy spells during the first two days or so, but I got better, so I have been feeling good since then.

Interviewer: Would you say you feel about the same as you did two weeks, two months after you started treatment, or are you feeling stronger than you did then?
Translator: *Ungathi uziva usafana kune veki okanye iinyanga ezimbini emva kokuba uziqalile ezipilisi okanye kukho umahluko omkhulu kunangoko wawusando kuziqala, uziva usemandleni kunangoko?*

Zoleka: *Zindinike amandla kakhulu kuba ndandingakwazi nokwenzani ndiyakwazi ukusebenza ngoku newashing ndiyazenzela.*
Translator: I think ... I think I have gotten stronger now because I do my own laundry, I can wash, I can do everything....
Zoleka: *Nempahla ebendikade ndingayinxibi ndiyayinxiba ngoku yayinkulu ndingasayinxibi.*
Translator: And I've put on some weight now because I'm back to the clothes I haven't worn in a long time because they were big.

Interviewer: Can you remember when the last time was when you felt as strong and healthy as you do now?
Translator: *Wagqibela nini ukuziva uphile ngoluhlobo uphile ngalo ngoku awusakhumbuli, ungathi wagqibelanini?*

Zoleka: *Ndagqibela ngoku ndandingeka fumani lengxaki ukuziva ndiphile oluhlobo ndiphile lona ndathi kengoku ndisakutya ezipilisi ndaphinda ndalolahlobo bendililulo.*
Translator: I last felt this healthy before I got this problem (HIV) and after I started with the medication I became healthy again.

Interviewer: And how is it going with your ARVs? Do you remember when to take them?
Translator: *Zikuqhuba njani zona iARVs uyawakhumbula amaxesha akho?*

Zoleka: *Ewe, ndiyazitya ngo eight wasekuseni na late, andiwalibali lonke ixesha.*
Translator: I don't forget them. I take them at 8 o'clock in the morning and 8 o'clock in the evening.

Interviewer: You said you have a radio alarm to remind you. Do you still have that?
Translator: *Usazi khumbuza ngala alarm iseradweni amaxesha akho?*

Zoleka: *Ewe ndisazikhumbuza, kangangoba ndihamba enkonzweni lankozo iphuma u 8, ithi xa iphuma yo ke ndingene endaweni enetap, ipilisi zam ndihlel ndiziphethe ke, ndiziphokozile xa kufike elaxesha ndisele ipilisi.*
Translator: I remind myself because I attend church services every evening and we finish at about 8 o'clock. So I always carry my medication. So after the service I'll just get some water and take my medication.

Interviewer: Have you been attending this church for a while?
Translator: *Kudala uhamba le cawa?*

Zoleka: *Ewe, kudala ndiyihamba ba yayihanjwa ngulomyeni wam engekasweleki nam ndangeniswa kuyo ke kude kube ngoku ndihamba yona.*
Translator: Yes, it's been quite a while, it was actually my husband's church before he died, he is the one who introduced me to it and I've been there since.

Interviewer: And how often do you go to the church?
Translator: *Uyakangaphi ecaweni?*

Zoleka: *Iyaqho lonke ixesha, akunamini kuthiwe uphumle.*
Translator: Everyday actually, they don't give us a break (Zoleka: *uphumla uLwesihlanu qha ePostile)* It's only on Fridays that we don't get to go there.

Interviewer: Do you walk there on your own?
Translator: *Uyazihambela ngenyawo ukuya pha?*

Zoleka: *Ewe, ayikudanga.*
Translator: Yes, it's not very far.

Interviewer: Is there anyone in the church who knows about your HIV status?
Translator: *Ukhona umntu ecaweni okwaziyo ukuba unalentsholongwane yeHIV?*

Zoleka: *Akukho nomnye ondaziyo, ndizazi ndodwa, nalomntana lo useKraaifontein qha.*
Translator: Not a single one of them knows, it's only my daughter in Kraaifontein and myself who know.

Interviewer: I remember you saying to me for the first time I spoke to you, that you were planning to tell other people.
Translator: *Ukugqibelana kwethu ukuthetha wawuthe usacinga ngokuba ungakwazi ukuxelela abanye abantu.*

Zoleka: *Ewe, ndanditshilo ndathi ndingakwazi ukumxelela umama wam ba abanye abantu banondithuka ngalangxaki ndinayo.*
Translator: Yes, I did say that I was planning to disclose to my mother, but not other people because they might be sarcastic about it.

Interviewer: So is it a fear of what other people will say or do that made you change your mind?

Translator: *Ingaba luloyiko lokuba abantu bazakuthuka ngayo lento, lento ibenza ukuba bangakuxeleli?*

Zoleka: *Ewe ndiyaboyika lento kuba abantu baske bayithathele phezulu lento yokuba unengxaki ethile yalento. Aske athi xa ethuka akuthuke ngalanto.*

Translator: Yes, I do fear that, because people take it differently when you disclose to them, as if you are giving them a reason to insult you about it.

Interviewer: Do you think that there is anything that will make you change your mind, any situation that will make you disclose?

Translator: *Ikhona into enokwenza uxelele abantu ngale meko yakho, into enokutshintsha ingqondo yakho? (Zoleka: Njani?) Into enokwenza ukuba ufune ukuxelela abantu ukuba unalento?*

Zoleka: *Andinakukwazi ukuxelela abantu umntu edinokumxelela ngumama lo usemaxhoseni, ndimxelele ingxaki yam esemaxhoseni ba ndinento ethile. Kuba umntu ndizakumxelela ahambe ehlikisa ngam apha esithubeni kanti naye akazazi ukuba akanayo lengxaki ndinayo.*

Translator: No, I won't be able to disclose to anyone but my mother. I want to tell her what happened to me when I got here in Cape Town. Because if I tell other people they'll start talking about me, making me a laughing stock, forgetting that they might be having it themselves.

Interviewer: I don't know if you would agree with me, maybe the fact that you are so healthy, you don't really need to tell anyone, you don't really need anyone's help. Would you agree with that?

Translator: *Andazi nokuba uyavumelana na nathi xasisithi lento yokuba uphilile, ubukeka uphilile umhle so awuboni sikhona isidingo sokuba uxelele abantu kuba awuguli mos awuka funi ncedo lwabo.*

Zoleka: *Hayi xandizijongile andiguli mos akukho need yoba ndixelele abantu, ngoba ke umntu ndizakumxelela ahlekise ngam, kanti mna akukhonto ndiyivayo kum ndiziphilele. Kanti mna lanto zange ndiyi fake entlokweni yam mna lanto ngoba ndiyazi ukuba isisifo esikhoyo kuwowonke umntu. qha xa wuzixelile ke umntu uske ahlekise ngawe.*

Translator: I actually feel very healthy at the moment. I don't really see a need to tell other people, I'm not prapared to have people laugh at me while I am feeling this healthy. I don't really think about my status because I know it's a common illness, everyone has it.

Interviewer: So there is no point of disclosing?

Translator: *Awuyiboni ineed yokuxelela abantu?*

Zoleka: *Hayi.*

Translator: No.

of women received childcare support from a partner (not necessarily the child's father; n=6, 3.8%).

Social support and coping strategies

Perceived availability of social support (raw scores)

Statistic	Total	Tangible support	Affectionate support	Positive social interaction	Emotional/ informational support
Mean	80.48	20.12	12.64	15.05	32.67
Std. Deviation	11.41	3.44	2.23	3.41	4.84
Minimum	36	10	3	4	13
Maximum	100	25	15	20	40
Skewness	-.61	-.63	-1.19	.44	-.60
Kurtosis	1.10	.26	1.69	-.47	1.24

Satisfaction with social support (raw scores)

Statistic	Total	Tangible support	Affectionate support	Positive social interaction	Emotional/ informational support
Mean	18.65	4.70	2.86	3.41	7.70
Std. Deviation	2.41	.81	.46	1.002	1.91
Minimum	2	0	0	0	1
Maximum	20	5	3	4	8
Skewness	-3.68	-3.41	-3.60	-1.574	-4.54
Kurtosis	19.42	12.98	13.76	1.376	23.86

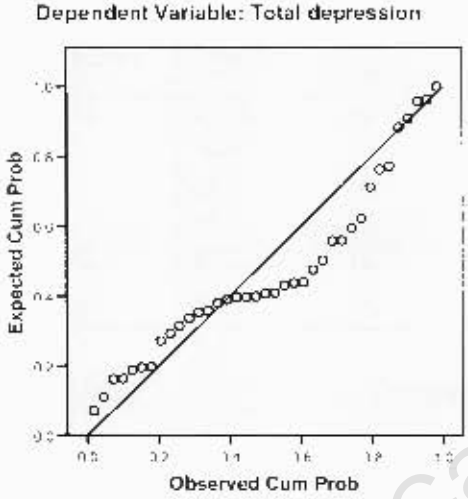
Coping strategies: raw scores

Statistic	Active coping	Avoidant coping	Religion & self-distraction	Substance use	Humour
Mean	37.39	9.68	16.59	2.32	3.11
Std. Deviation	5.01	3.19	2.55	1.05	1.23
Minimum	24	7	8	2	2
Maximum	48	21	20	8	8
Skewness	.18	1.57	-.87	3.89	.83
Kurtosis	-.56	2.22	.65	15.79	

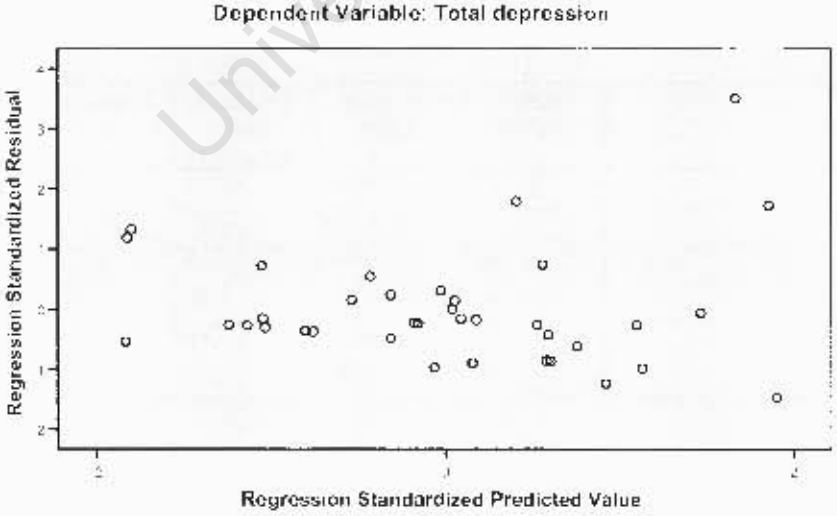
Diagnostics for multivariate analysis

Question 2.5 depression and anxiety models

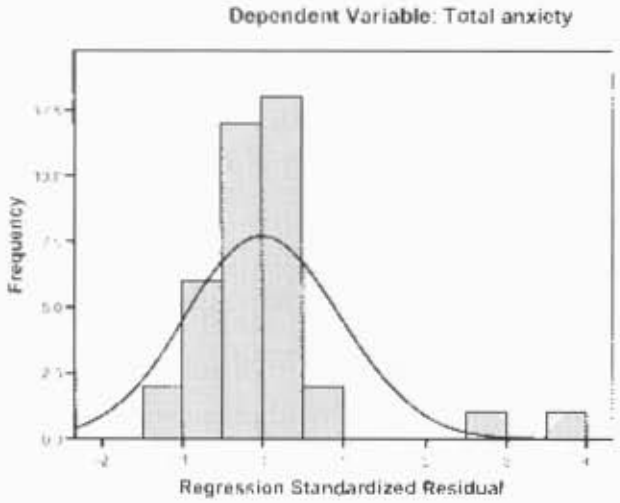
Normal P-P Plot of Regression Standardized Residual



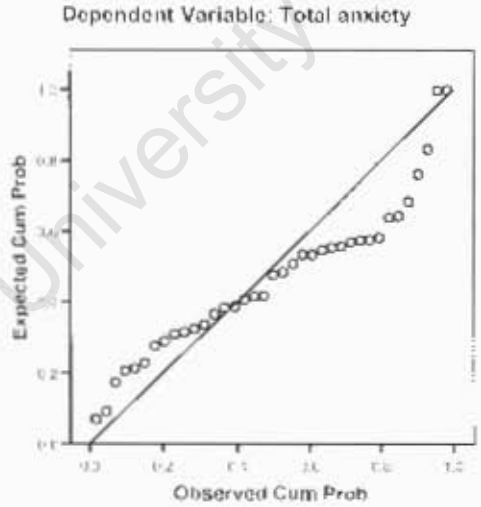
Scatterplot

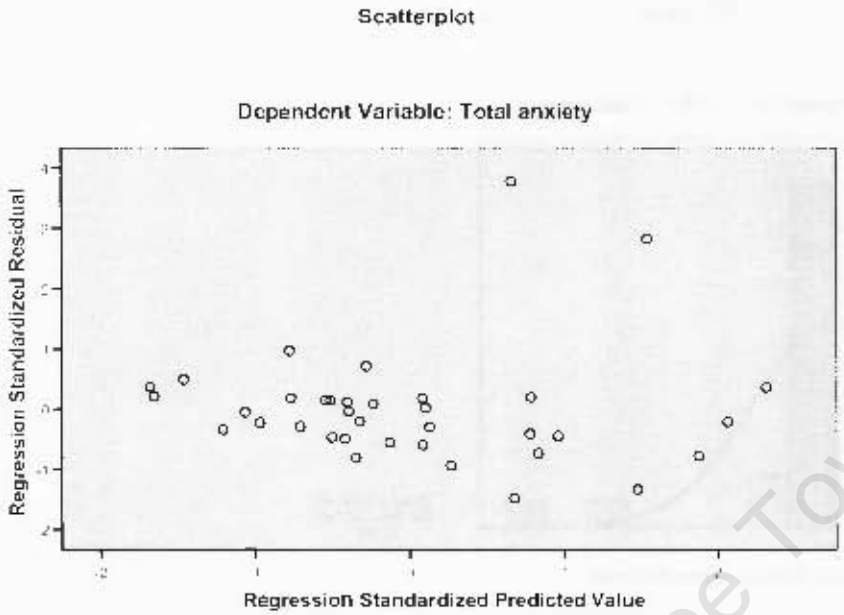


Histogram

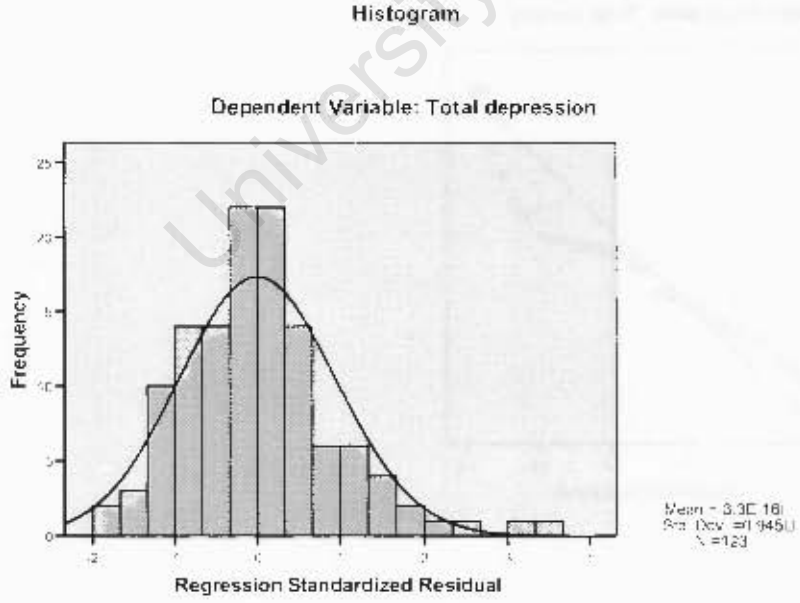


Normal P-P Plot of Regression Standardized Residual

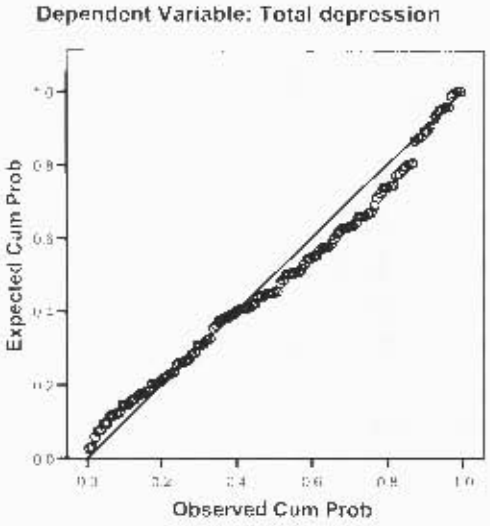




Question 3 depression and anxiety models



Normal P-P Plot of Regression Standardized Residual



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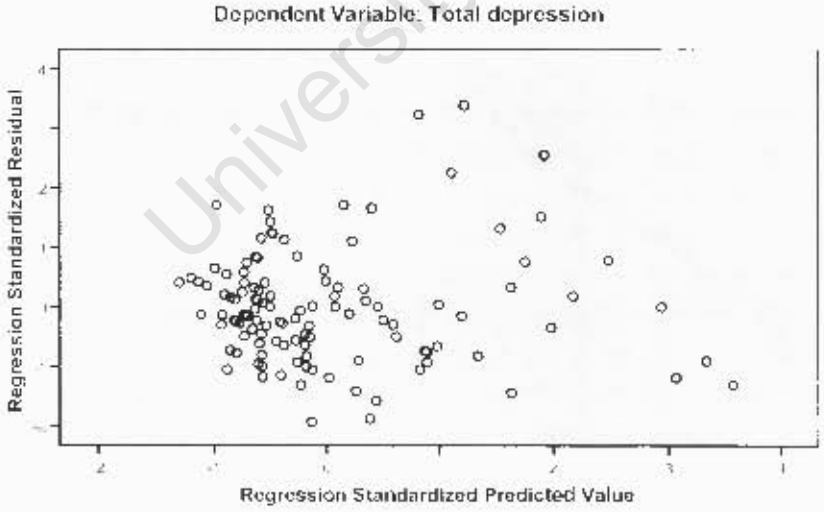
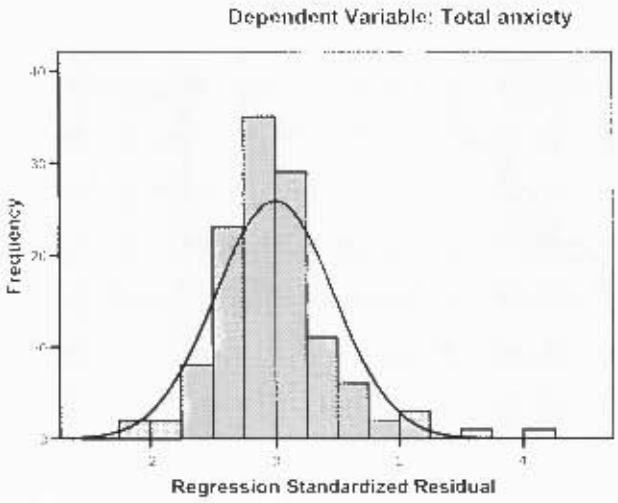
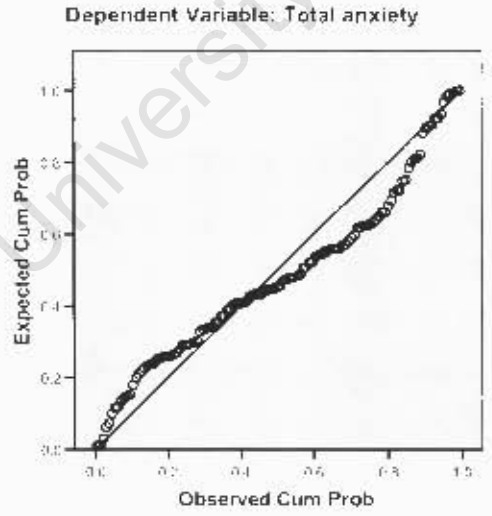
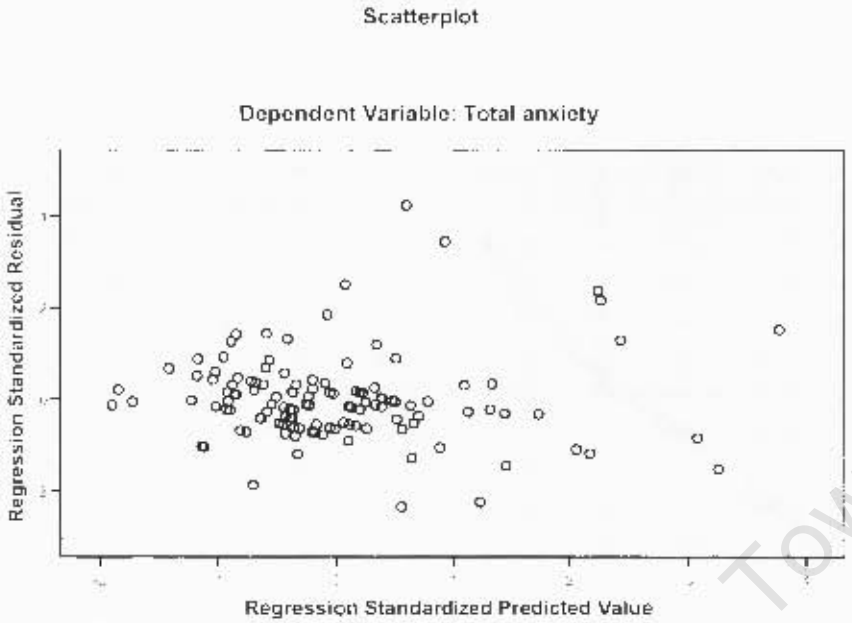


Histogram

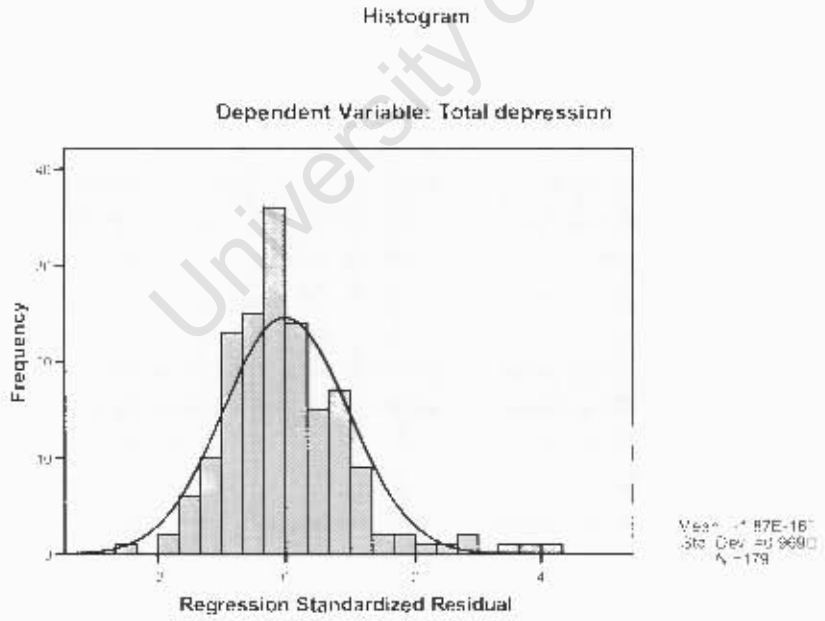


Normal P-P Plot of Regression Standardized Residual

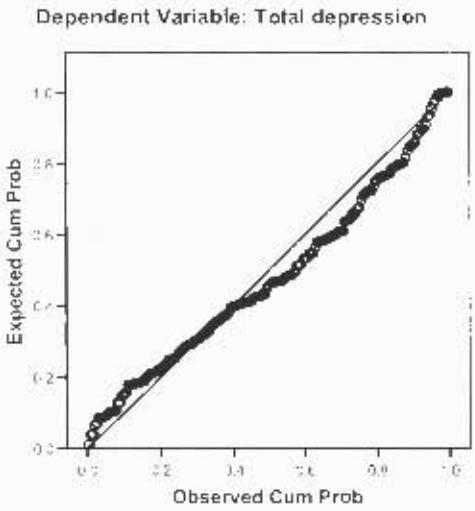




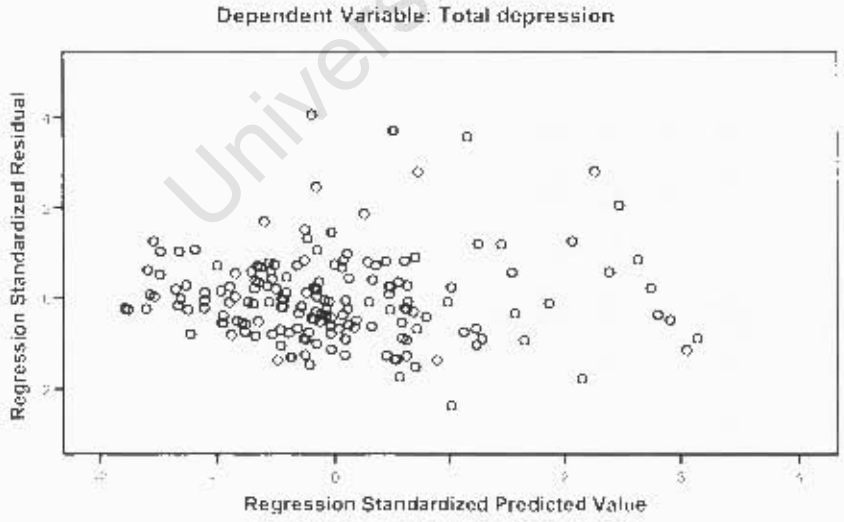
Question 4 depression and anxiety models



Normal P-P Plot of Regression Standardized Residual



Scatterplot



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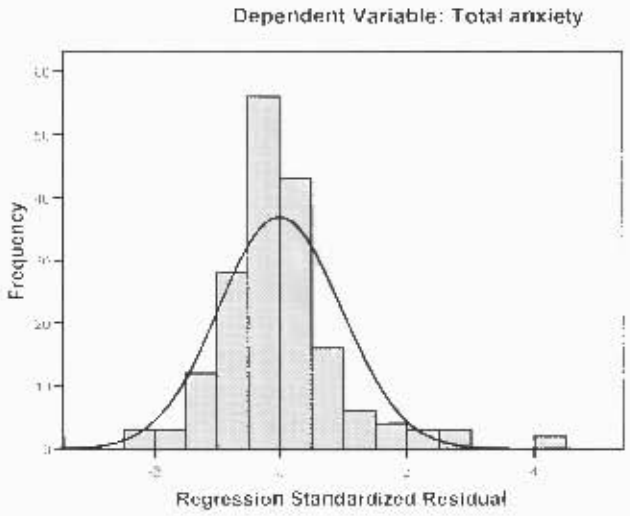
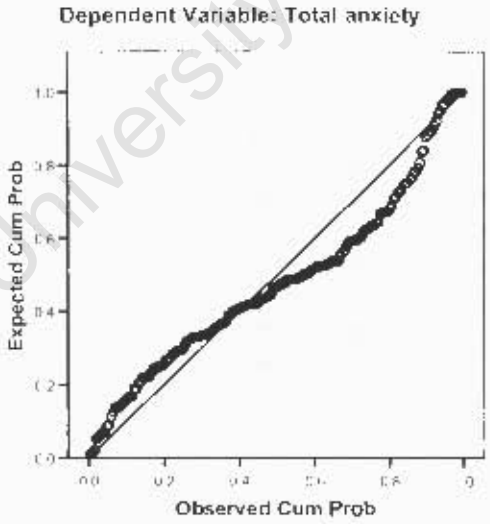
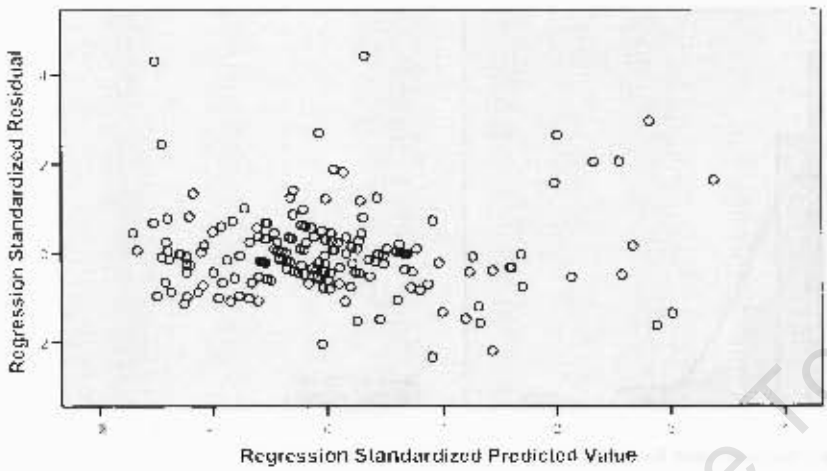


Normal P-P Plot of Regression Standardized Residual



Scatterplot

Dependent Variable: Total anxiety



Appendix L. Comparison of statistical results I (questions 1-2.4)

Using parametric and non-parametric tests, and excluding somatic items from depression scores

Research question	Type of test	Planned comparison	Depression	Depression (excl. somatic)	Anxiety
1.1	Parametric	Linear contrast	**p=.000**	**p=.000**	**p=.003**
	Non-parametric	Mann-Whitney	**p=.000**	**p=.000**	**p=.000**
1.2	Parametric	HIV- / Asymp	**p=.015**	**p=.002**	p=.237
		HIV- / Symp	**p=.000**	**p=.000**	**p=.005**
		HIV- / AIDS	**p=.000**	**p=.000**	**p=.002**
		Asymp / Symp	p=.912	p=.971	p=.647
		Asymp / AIDS	p=.847	p=.680	p=.480
		Symp / AIDS	p=.586	p=.431	p=.657
	Non-parametric (Kruskall-Wallis)	HIV- / Asymp	**p=.002**	**p=.000**	**p=.011**
		HIV- / Symp	**p=.000**	**p=.000**	**p=.001**
		HIV- / AIDS	**p=.000**	**p=.000**	**p=.000**
		Asymp / Symp	p=.840	p=.839	p=.715
		Asymp / AIDS	p=.911	p=.979	p=.366
		Symp / AIDS	p=.747	p=.901	p=.181
2.1	Parametric	Linear contrast	p=.559	p=.394	p=.475
	Non-parametric	Kruskall-Wallis	p=.906	p=.511	p=.273
2.2	Parametric	Linear contrast	p=.104	p=.140	p=.201
	Non-parametric	Kruskall-Wallis	**p=.028**	**p=.056**	**p=.030**
2.3	Parametric	Linear contrast	**p=.036**	**P=.026**	p=.546
	Non-parametric	Kruskall-Wallis	**p=.048**	**P=.035**	p=.096
2.4	Parametric	Linear contrast	**p=.015**	**p=.001**	**p=.001**
	Non-parametric	Kruskall-Wallis	**p=.000**	**p=.000**	**p=.000**

Bold: p<0.05

Appendix M. Comparison of statistical results II (questions 2.5-4)

Using log transformation on DV, excluding somatic items from depression scores, and the inclusion of additional predictor variables (model 2)

Depression models:

Q	Regression models		Model 1		Model 1: Log of DV		Model 1: No somatic items		Model 2	
			p/R^2	Std β	p/R^2	p/R^2	p/R^2	Std β	p/R^2	Std β
2.5	Predictors	Change CD4 count	p .388	-	p .329	-	p .156			-
		Change percep. health	p .315		p=.921	-	p=.135		-	-
		Change # side effects	p=.993	-	p=.888	-	p .032		-	-
	Variance explained	Unadjusted	R^2=.063		R^2=.033		R^2 .049		-	
		Adjusted	R^2=-.023		R^2=-.055		R^2=-.037			
3.	Predictors	Age	p=.362	-	p=.455	-	p .350	-	p=.251	
		Education deprivation	p .287		p .468		p=.693		**p=.240**	-
		Income/material depr.	p .635	-	p=.726	-	p .503	-	p .643	-
		Regularity HH income	*p=.053*	-	p=.500	-	p .218	-	p=.119	
		CD4 count	p .310	-	p .421		p=.145		p=.291	-
		ART status	p .641		p=.678	-	p .578	-	p .772	-
		Recent hospitalisation	p .289		p=.372	-	p .380	-	p .302	-
		Percep. physical health	**p=.036**	β =-.174	**p=.007**	β =-.244	**p .011**	β -.221	p=.120	-
		Attend HIVsupport grp	*p .082*		p .195	-	*p=.053*	-	p=.129	-
		Total satisfaction	p .559	-	p .433		p=.439		**p=.620**	-
		Avoidant coping	**p .000**	β =.436	**p .000**	β =.401	**p=.000**	β =.402	**p=.000**	β .450
		Substance use	p=.326	-	p=.336	-	p .370	-	p=.471	-
		Humour	p .932	-	p .850		p=.855	-	p=.971	-
		HIV+ child	-	-	-	-	-	-	p .378	-
		Time since diagnosis	-	-	-	-	-	-	p=.563	-
	Variance explained	Unadjusted	R^2=.496		R^2=.404		R^2=.447		R^2=.482	
		Adjusted	R^2 .436		R^2 .333		R^2 .381		R^2 .406	
4.	Predictors	Age	p=.350	-	p=.676	-	p .701	-	p .292	-
		Education deprivation	**p=.019**	β -.143	**p=.049**	β -.128	*p=.078*	-	**p .011**	β =-.156
		Income/material depr.	p .944	-	p .946	-	p=.754		p=.993	-
		Regularity HH income	**p .009**	β .179	p=.296	-	p .125	-	**p=.008**	β =.182
		HIV status	**p=.050**	β =.174	**p=.019**	β .222	**p .039**	β .187	**p .053**	β =.171
		Recent hospitalisation	p .568	-	p .900		p=.613		p=.481	-
		Percep. physical health	**p=.028**	β -.192	**p=.008**	β =-.249	**p=.009**	β =.233	**p=.051**	β =-.172
		Total satisfaction	**p=.028**	β =-.133	*p=.069*	*β =-.117*	**p=.008**	β =.362	**p=.029**	β -.132
		Avoidant coping	**p=.000**	β =.399	**p=.000**	β .361	**p=.000**	β .352	**p=.000**	β .389
		Substance use	**p=.021**	β =.126	p=.137	-	**p .010**	β .144	**p .015**	β =.133
		Humour	*p .076*	β .105	p .180	-	**p=.044**	β =.119	**p=.044**	β =.118
		HIV + child			-	-	-	-	p .123	-
	Variance explained	Unadjusted	R^2=.522		R^2=.468		R^2=.504		R^2=.529	
		Adjusted	R^2 .490		R^2 .432		R^2 .472		R^2 .495	

Bold: p<0.05 Italics: 0.05<p<0.10

Anxiety models:

Q	Regression models		Model 1		Model 1: Log of DV		Model 2	
			p/R^2	Std β	p/R^2	Std β	p/R^2	Std β
2.5	Predictors	Change CD4 count	p=.801	-	p=.866	-	-	-
		Change percep. health	p=.516	-	p=.782	-	-	-
		Change # side-effects	p=.435	-	p=.388	-	-	-
	Variance explained	Unadjusted	R^2=.041		R^2=.031		-	
		Adjusted	R^2=.047		R^2=.057			
3.	Predictors	Age	p=.693	-	p=.876	-	p=.663	-
		Education deprivation	p=.714	-	p=.842		p=.611	
		Non-HH partner	p=.175	-	p=.163	-	p=.172	-
		HH partner	p=.773	-	p=.687	-	p=.663	-
		CD4 count	p=.892		p=.872	-	p=.818	-
		Percep. physical health	p=.883	-	p=.846	-	p=.783	-
		ART status	p=.193	-	p=.135		p=.264	
		Total support	p=.782	-	p=.781	-	p=.741	-
		Total satisfaction	p=.497		p=.849	-	p=.470	-
		Active coping	**p=.002**	β=-.335	**p=.002**	β=-.332	**p=.002**	β=-.336
		Avoidant coping	**p=.000**	β=.365	**p=.000**	β=.347	**p=.000**	β=.355
		Substance use	*p=.096*	β=.138	*p=.082*	β=.141	*p=.085*	β=.144
		Income/material depr.	-	-	-	-	p=.695	-
		HIV+ child	-	-	-	-	p=.370	
	Variance explained	Unadjusted	R^2=.335		R^2=.333		R^2=.341	
		Adjusted	R^2=.263		R^2=.260		R^2=.256	
4.	Predictors	Age	p=.310	-	p=.244		p=.225	
		Education deprivation	p=.416	-	p=.557	-	p=.351	-
		Non-HH partner	p=.324		p=.364	-	p=.285	-
		HH partner	p=.588	-	p=.609		p=.712	
		HIV status	p=.608	-	p=.240	-	p=.584	-
		Percep. physical health	p=.266	-	p=.277	-	p=.311	-
		Total support	p=.245	-	*p=.079*	β=-.176	p=.310	-
		Total satisfaction	p=.536	-	p=.998		**p=.524**	
		Active coping	p=.186	-	**p=.231**	-	p=.134	-
		Avoidant coping	**p=.060**	β=.365	**p=.000**	β=.362	**p=.000**	β=.365
		Substance use	**p=.000**	β=.231	**p=.001**	β=.205	**p=.000**	β=.235
		Income/material depr.	-	-	-	-	p=.310	-
		HIV+ child		-	-	-	p=.280	-
	Variance explained	Unadjusted	R^2=.362		R^2=.371		R^2=.370	
		Adjusted	R^2=.320		R^2=.329		R^2=.320	

Bold: p<0.05
Italics: 0.05<p<0.10

Appendix N. Sensitivity testing on computation of income and material deprivation

Respondent no.	Note on unknown HH member income	HH income	Approx. new equivalised HH income	Change to equivalised HH income?	Material or income deprivation?	New material or income deprivation	Change to material or income deprivation?
6	The brother-in-law is a contractor.	R 780	R 488	R 298	yes	yes	no
22	One salary of R5000 is not used to help the household financially.	R 6,840	R 800	R 2,174	no	yes	yes
24	The brother works at a bakery.	R 1,240	R 659	R 293	yes	yes	no
36	Additional income of an unknown amount for piecework of HH member.	R 1,740	R 546	R 122	yes	yes	no
41	The sister is a cleaner at the hospital.	R 960	R 714	R 371	yes	yes	no
48	Sister is employed as a domestic worker.	R 1,740	R 641	R 195	yes	yes	no
52	The cousin works as a painter but does not contribute to the household.	R 0	R 0	R 0	yes	yes	no
57	Her step-father is a painter who she estimates earns more than R1000 a month.	R 860	R 476	R 271	yes	yes	no
59	Uncle who lives in HH works as an electrician.	R 2,860	R 714	R 335	yes	yes	no
65	Two household members work as shop assistants.	R 100	R 408	R 388	yes	yes	no
66	The cousin is a casual worker on a farm and his income is variable.	R 1,580	R 636	R 158	yes	yes	no
80	The two sons work as a librarian and Sunday school teacher. Both salaries are unknown.	R 330	R 1,515	R 1,415	yes	no	yes
96	The brother's income is unknown but he does help financially.	R 1,280	R 893	R 436	yes	yes	no
126	The aunt is employed as a nurse and is the breadwinner in the house.	R 1,480	R 2,143	R 1,614	yes	no	yes
142	The cousin works as a contractor and is the main breadwinner	R 1,140	R 968	R 600	yes	yes	no
143	Her sister works at a restaurant.	R 2,080	R 909	R 279	yes	yes	no
167	The father works as a policeman and is the breadwinner in the house.	R 180	R 1,042	R 1,004	yes	yes	no
179	The sister is employed as a domestic worker.	R 0	R 357	R 357	yes	yes	no
n=18				**R 5,963**			**n=1 less case**